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Award Number: W81XWH-06-1-0334

TITLE: Barriers to Breast Cancer Screening Among Latinas in the U.S.- Mexico Border Region

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REPORT DATE: May 2011

TYPE OF REPORT: Final

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

REPORT DOCUMENTATION PAGE

Form Approved
OMB No. 0704-0188

1. REPORT DATE *(DD-MM-YYYY)*	2. REPORT TYPE	3. DATES COVERED *(From - To)*
01-05-2011	Final	1 MAY 2006 - 30 APR 2011

4. TITLE AND SUBTITLE
Barriers to Breast Cancer Screening Among Latinas in the U.S.-Mexico Border Region

5a. CONTRACT NUMBER

5b. GRANT NUMBER
W81XWH-06-1-0334

5c. PROGRAM ELEMENT NUMBER

6. AUTHOR(S)
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5d. PROJECT NUMBER

5e. TASK NUMBER

5f. WORK UNIT NUMBER

7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES)
University of Texas-Pan American
Edinburg, Texas 78539

8. PERFORMING ORGANIZATION REPORT NUMBER

9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES)
U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

10. SPONSOR/MONITOR'S ACRONYM(S)

11. SPONSOR/MONITOR'S REPORT NUMBER(S)

12. DISTRIBUTION / AVAILABILITY STATEMENT
Approved for Public Release; Distribution Unlimited

13. SUPPLEMENTARY NOTES

14. ABSTRACT

The purpose of this project is to establish a research and training collaborative partnership between the Institute for Population Health Policy (IPHP) at the University of Texas-Pan American (UTPA) and the Leonard Davis Institute of Health Economics (LDI) at the University of Pennsylvania (Penn). Our objectives and scope are: to develop a competitive and successful breast cancer research program that focuses in cancer control and population sciences at UTPA; to develop and complete a research project on barriers to breast cancer screening among Latinas in the U.S.-Mexico border region; to develop the research infrastructure that will enable UTPA investigators to submit competitive breast cancer research proposals. The development of this partnership has been very successful during the five years of this project. The partnership has allowed UTPA researchers to improve their research skills and collaborate in manuscripts and research proposals. These activities will allow this collaboration to continue and further develop over the next few years.

15. SUBJECT TERMS
Breast cancer screening; Latinas

16. SECURITY CLASSIFICATION OF:			17. LIMITATION OF ABSTRACT	18. NUMBER OF PAGES	19a. NAME OF RESPONSIBLE PERSON
a. REPORT	b. ABSTRACT	c. THIS PAGE			USAMRMC
U	U	U	UU	82	19b. TELEPHONE NUMBER *(include area code)*

Table of Contents

INTRODUCTION

The subject/purpose of this project is to establish a research and training collaborative partnership between the Institute for Population Health Policy (IPHP) at the University of Texas-Pan American—a Minority Institution—and the Leonard Davis Institute of Health Economics (LDI) at the University of Pennsylvania (Penn). The UTPA-Penn breast cancer research/training partnership focuses on understanding and ameliorating disparities in breast cancer screening among Latinas in the U.S.-Mexico border region. Our objectives and scope are (1) to develop a competitive and successful breast cancer research program that focuses in cancer control and population sciences at UTPA; (2) to develop and complete a research project on barriers to breast cancer screening among Latinas in the U.S.-Mexico border region; (3) to develop the research infrastructure that will enable UTPA investigators to submit competitive breast cancer research proposals.

BODY

The Statement of Work for the project includes the following three tasks:

(1) Develop a competitive and successful breast cancer research program that focuses in cancer control and population sciences at UTPA (Years 1 and 2)
(2) Develop and complete a research project on barriers to breast cancer screening among Latinas in the U.S.-Mexico border region (Years 3 and 4)
(3) Develop the research infrastructure that will enable UTPA investigators to submit competitive breast cancer research proposals (Year 4)

We have been able to accomplish our set goals and objectives during the five years of the project. Our task for the first two years of the project involved the development of a competitive and successful breast cancer research program that focuses in cancer control and population sciences at UTPA. During Year 1, Drs. Brown, Hinojosa and Pagán took summer courses at Penn in 2006. The courses centered on cancer research lectures and seminars within the clinical research summer program at Penn. Drs. Brown, Hinojosa and Pagán were able to take courses on Database Management, Fundamentals of Biostatistics, Introduction to Epidemiologic Research Methods, and Clinical Trials and Translational Research. Dr. Bastida was unable to participate in the program due to a previous research-related commitment in South Africa.

Dr. Angela DeMichele (Co-Investigator in this project) is the Director of the Clinical/Translational Research Training Program in the Division of Hematology/Oncology and she taught one of the courses (Clinical Trials and Translational Research) and assisted UTPA faculty during the summer experience at Penn. The summer program allowed for opportunities for UTPA investigators to meet face-to-face with Penn investigators and to discuss the research hypotheses, survey design, IRB and other issues related to the research project on border breast cancer screening practices.

Drs. Asch, Armstrong and Guerra guided the research project and served as mentors and research collaborators to UTPA faculty members. We conducted a meeting at Penn in July 2006 to discuss the structure of the research project on breast cancer screening in the border region (Drs. Asch, Armstrong, Guerra, Pagán, Hinojosa and Brown participated). At the invitation of Dr. Asch, Dr. Pagán presented a seminar in February 2007 at Penn for the Robert Wood Johnson Health & Society Scholars Program. Dr. Pagán discussed his research agenda in health care economics and gave RWJF Health & Society Scholars a general perspective of the collaborative projects between UTPA and Penn, including the HBCU/MI Partnership Training Award.

Tasks 2 and 3 of the Statement of Work involved the development and completion of a research project on barriers to breast cancer screening among Latinas in the U.S.-Mexico border region (years 3 and 4) and the development of a research infrastructure at UTPA that will enable investigators to submit competitive breast cancer research proposals (year 4). We made some progress during Year 1 in these tasks by developing a survey instrument (and informed consent form) to identify sociodemographic correlates of underutilization of mammography screening among Latinas in the U.S.-Mexico border region. During this first year we were also in the process of receiving IRB approval to conduct the study, which included the recruitment of 877 study participants based on the sample design and sample of the Border Epidemiological Study on Aging (BESA). All the IRB paperwork was submitted both to the UTPA IRB for expedited review and to the Department of Defense for pre-review.

The best evidence that this collaborative partnership between UTPA and Penn was successful during Year 1 included the submission in 2007 of a manuscript on breast cancer screening and health insurance coverage. This paper was under review in *Medical Care* and included two faculty members from UTPA (Pagán and Brown) and three from Penn (Asch, Armstrong and Guerra) that were part of this HBCU/MI Partnership Training Award. The paper evaluated how the proportion of the local population without health insurance coverage was related to whether adult women undergo mammography screening within the past year. The research team used data from the 2000-2001 Community Tracking Study Household Survey, a national study developed to track changes the local health care systems of 60 U.S. communities and representative of households in the contiguous 48 states (59,725 participants). The analyses included women 40 to 69 years of age who participated in the 2000-2001 Community Tracking Study Household Survey (12,595 participants). The main outcome measure was whether or not the respondent had a mammogram within the past year. Regardless of their own insurance coverage, women ages 40 to 69 were less likely to report that they had a mammogram within the last year if they

resided in communities with a relatively high uninsurance rate, after adjusting for other individual and community-level variables that could be associated with mammography screening. A 10 percentage-point decrease in the proportion of the local insured population is associated with an 18.3 percent decrease in the likelihood that a woman ages 40-69 will undergo mammography screening within a year. The study found that women living in communities with high uninsurance were substantially less likely to undergo mammography, whether or not they have health insurance coverage themselves. These results were consistent with the view that the negative impact of uninsurance extends to everyone in the community regardless of individual health insurance status.

During Year 2 we were able to complete our survey instrument on breast cancer screening and on 23 July 2007 we received approval to conduct our study from the Institutional Review Board at UTPA. The protocol was reviewed by the USAMRMC's Office of Research Protections (Human Research Protection Office) and found to comply with applicable Federal, DOD, U.S. Army, and USAMRMC human subjects protection requirements (approved 24 July 2007; HRPO Log Number A-13729). We began data collection efforts during Year 2 and completed data collection in Year 3. A total of 738 interviews were conducted by ten trained interviewers between January and June 2008. Study participants were selected from the Border Epidemiologic Study on Aging (BESA), a longitudinal survey of Latino/a adults in South Texas.

During Year 3 we spent a substantial amount of time in data management, coding, computer programming, and statistical modeling/analysis. The mean age of study participants was 63 (with a standard deviation = 13). Seventy percent of participants had less than a high school education, 16 percent had a high school diploma or GED, and 14 percent had more than a high school education. Fifty-seven percent of respondents were married and the 42 percent had an annual household income of $10,000 or less. Twenty-six percent of survey participants did not have any form of health insurance coverage. Ninety-six percent of participants had heard of mammography and 44 percent began to get breast cancer screening between the ages of 40 and 50. Eighty-one percent had a mammogram done within the past one or two years and 77% know where to go for mammography screening. Only 17 percent knew when a self-breast exam should be performed with respect to menses. Our preliminary analysis during Year 3 suggested that health literacy levels in our South Texas Latina sample were very low and that there were substantial differences in knowledge, attitudes, and behaviors about mammography and breast cancer screening between women classified as having adequate versus inadequate functional health literacy levels (which is based on respondents' answers to the Short Test of Functional Health Literacy in Adults (STOFHLA)).

The tasks in Year 3 also involved the development of research infrastructure at UTPA that would enable investigators to submit competitive research proposals. We continued our work on the projects funded through an R24 grant from the Agency for Healthcare Research and Quality (AHRQ). This AHRQ research infrastructure grant funded several pilot projects in health services research (community uninsurance and health care access, the use of health care services in the U.S.-Mexico border region, severe weather and health care use by low-income and uninsured vulnerable populations, and the cost-effectiveness and net-benefits of school-based health promotion programs). The AHRQ health services research initiative also actively promoted the development of research projects by junior faculty and graduate students focusing on the U.S. Latino population. These projects are consistent with the goals and objectives of not only AHRQ and the UTPA health services research initiative but also with the goals and objectives of this HBCU/MI Partnership Training Award.

Two papers related to cancer were published during Year 3: Chao, Li-Wei, José A. Pagán and Beth J. Soldo. (2008). "End-of-Life Medical Treatment Choices: Do Survival Chances and Out-of-Pocket Costs Matter?" *Medical Decision Making*, 28(4), 511-523; and Guerra, Carmen E., Phyllis A. Gimotty, Judy A. Shea, José A. Pagán, J. Sanford Schwartz and Katrina Armstrong. (2008). "Effect of Guidelines on Primary Care Physician Use of PSA Screening: Results from the Community Tracking Study Physician Survey," *Medical Decision Making*, 28(5), 681-689. DOD support was gratefully acknowledged and noted in the two papers. They are also examples of the close collaborative research partnership between UTPA and Penn built through this HBCU/MI Partnership Training Award.

During Year 4 we experienced several transitions in the UTPA research team. Dr. Cynthia Brown became the Principal Investigator of this partnership training award. Dr. José A. Pagán, the previous Principal Investigator, continued to be involved in the initiative as Co-Investigator. He is a Research Professor at UTPA and Professor and Chair in the Department of Health Management and Policy, School of Public Health, University of North Texas Health Science Center. Research activities related to the survey data collected on barriers to breast cancer screening among Latinas in the U.S.-Mexico border region continued during Years 4 and 5.

We received a one-year no cost extension on this project by the USAMRMC on 25 May 2010. The Year 5 Statement of Work included three tasks:

(1) To work collaboratively to complete three manuscripts on mammography screening among Latinas in the U.S.-Mexico border region;
(2) To identify other funding sources that will support breast cancer research; and
(3) To transfer technical knowledge and know-how about breast cancer research from Penn to UTPA.

Subtask 1.1

Subtask 1.1 was led by Dr. Brown and it focused on assessing the factors that influence the decision to have a mammogram and the role of health care system distrust on mammography screening rates. Work on this project was completed and the paper was submitted to the *American Journal of Preventive Medicine* on 15 February 2011. The coauthors of the study are Drs. Brown (UTPA), Pagán (UTPA/UNTHSC), Asch (Penn) and Armstrong (Penn). This paper gave an opportunity to the UTPA researchers to further develop their skills in breast cancer research and trust and distrust domains related to the health care system. The paper is entitled "Health Care System Distrust and Breast Cancer Screening: Results from a Survey of Mexican American Women in South Texas".

Breast cancer is the primary cause of cancer deaths for Hispanic women and 55% of the breast cancer cases for Hispanic women are diagnosed at the local stage compared to 63% of breast cancer cases for non-Hispanic white women.[1] Lower rates of breast cancer screening and follow up mostly account for these ethnic differences in breast cancer stage of diagnosis.[2,3] Compared to all other major racial/ethnic groups, Hispanic women aged 40 and older have the lowest two-year mammography screening rate in the country (59.6% compared to, for example, 68.1% for non-Hispanic whites), and the screening rate is even lower for Mexican American women (56.2%).[1] Thus, increasing the breast cancer screening rate of Mexican American women can significantly reduce the observed disparities in breast cancer morbidity and mortality between Hispanic and non-Hispanic white women.

Extant research has consistently shown that two of the most important breast cancer screening barriers are low income and lack of health insurance coverage.[4] Recent research also has shown that health literacy—the ability to appropriately understand health information in health care decision-making—may also be an important barrier to breast cancer screening.[5,6] Over the last few years, however, several studies have suggested that lack of trust in health care providers and the health care system may play a substantial role in health care seeking behavior.[7-10] In this context, trust can be defined as "the belief by an individual (the truster) that another entity (the trustee) would act in one's best interest in the future to prevent a potentially important negative outcome."[11] However, distrust may be a more important concept in health care decision-making. Distrust encompasses not only the lack or absence of trust but also the conviction that the trustee would behave against the best interest of the truster.[11]

This study examined the association between four domains of distrust (fidelity, competence, confidentiality and honesty) and the breast cancer screening behavior and adherence of Mexican American women from the Lower Rio Grande Valley (LRGV) of Texas. The LRGV not only has among the highest poverty and uninsured rates in the US, but this region of Texas also has very low breast cancer screening rates.[4,12] Previous studies have shown that distrust is related to lower medical treatment adherence, lower participation in clinical trials and unwillingness to undergo genetic testing for breast cancer risk.[13-15] A more recent study showed that distrust was related to the frequency of clinical breast exams but not mammography screening.[16] However, this study relied on a convenience sample of 184 English-speaking, urban women and the distrust scale used focused more on providers than on institutions or the health care system (e.g., two of the four questions included in the distrust scale were "I trust my healthcare providers" and "I've been treated poorly by healthcare providers more often than I've been treated with respect").[16] This distrust scale is also likely to suffer from simultaneity (endogeneity) bias (e.g., women who had a mammogram and received low quality care will also report poor treatment by health care providers). The primary hypothesis of this study is that some of the key domains of health care system distrust are likely to be related to low mammography uptake and adherence, even after controlling for other factors known to be related to breast cancer screening.

Seven hundred and thirty six Mexican American women 40 years of age and older were selected at random from the Border Epidemiologic Study on Aging (BESA) for in-depth interviews about mammography screening knowledge, attitudes and behaviors. The BESA is a population-based panel study of middle-aged and older Latinos/as from the LRGV of Texas (Cameron, Hidalgo and Starr counties). The panel study began in 1994 with 1,089 participants and additional respondents were added during additional data collection waves from 1998 to 2006.[17] Interviews were conducted at the homes of study participants in English or Spanish from January to June 2008. Written informed consent was obtained before conducting these interviews. A $30 gift card from a local supermarket was used to compensate study participants for their time. Interviews lasted from 20 to 30 minutes. The study protocol was approved by the Institutional Review Boards of the University of Texas-Pan American and the University of North Texas Health Science Center, and reviewed by the U.S. Army Medical Research and Materiel Command's Office of Research Protections, Human Research Protection Office.

The survey instrument included questions related to knowledge, attitudes and behaviors about mammography screening, demographic and socioeconomic information, and health care system distrust questions from a recently developed scale.[11] All survey participants were asked a general yes/no question "Have you ever had a mammogram?" Respondents who answered "yes" were then asked "When did you have your last mammogram?" and categorical responses to this question ("Within 1 year", "Between 1 and 2 years", "Between 2 and 3 years", "Between 3 and 5 years" and "More than 5 years") were recoded to create a binary adherence variable: whether or not the respondent reported a mammogram within the last year. "Don't know" and "No Answer" responses were excluded from the analysis.

The four domains of health care system distrust discussed above were measured with four questions: "Medical experiments can be done on me without me knowing about it" (honesty), "People can get access to my medical records without my approval" (confidentiality), "People die every day because of mistakes by the health care system" (competence) and "The health care system cares more about holding costs down than it does about doing what is needed for my health" (fidelity). Responses to these questions

were recoded from a five-point scale to a binary variable ("Strongly agree" and "agree" versus "Not sure", "Disagree" and "Strongly disagree"). These questions were developed to assess distrust in the health care system and health care institutions, not just distrust in providers.[11] A focus on the health care system and institutions rather than on providers also minimizes any simultaneity or co-determinacy concerns evident in related research.[16]

Other variables in our survey that are likely to be related to mammography screening and adherence include age (40-49, 50-59, 60-69 and 70 and above years of age), educational attainment (less than high school, high school and some college education or college graduate), marital status (married and not married), household income (more than $10,000 and less than $10,000 per year), health insurance coverage (insured and uninsured) and U.S. acculturation level. Acculturation was measured with the Short Acculturation Scale for Hispanics (SASH), a 12-question instrument reflecting language use, media and ethnic social relations.[18-20] Higher acculturation was defined as having a SASH average score of three points or higher.

Missing responses were imputed using a multiple imputation routine based on multivariate normal regression in Stata/MP 11.1.[21] Variables with imputed values included years of education (n=7), acculturation (n=1), household income (n=80) and health care system distrust (n=39). Missing values were imputed using an iterative Markov chain Monte Carlo (MCMC) method, based on a multivariate normal model and five imputations.[22] Responses with missing values were also excluded using casewise deletion but the results of the study did not change.

Table 1 describes the sample of 722 survey respondents. Eighty six percent of respondents reported ever having undergone mammography screening and 44% had a mammogram within the last year. Almost 84% of respondents agreed with the statement that medical experiments could be done to them without their knowledge, 77% agreed that people could get access to their medical records without their approval, 14% agreed that people die every day because of health care system mistakes and 23% agreed that the health care system cared more about controlling costs than about the health of patients. Seventeen percent of survey respondents were 40-49 years of age, 24% were 50-59 years of age, 25% were 60-69 years of age and 34% were 70 years of age or older. Seventy percent of respondents had less than a high school education, 58% were married and 58% earned less than $10,000 in household income per year. Twenty-seven percent of survey participants were uninsured and 79% had low US acculturation levels (as measured by their SASH scores).

Table 1: Characteristics of Respondents

	%		%
Mammography Screening		Marital Status	
Ever had a mammogram	85.46	*Married*	57.48
Had a mammogram within the last year	44.32	*Not married*	42.52
Health Care System Distrust		Household Income	
Medical experiments can be done on me without me knowing about it	83.87	*More than $10,000 per year*	41.74
People can get access to my medical records without my approval	76.74	*Less than or equal to $10,000 per year*	58.26
People die every day because of mistakes by the health care system	13.81	Health insurance coverage	
The health care system cares more about holding costs down than it does about doing what is needed for my health	22.91	*Insured*	73.27
Age		*Uninsured*	26.73
40-49 years	17.31	U.S. acculturation level	
50-59 years	23.55	*Lower (SASH score below 3)*	79.47

60-69 years	24.79	*Higher (SASH score equal to or above 3)*	20.53
70+ years	34.35		
Educational Attainment			
Less than high school	69.79		
High school	15.94		
Some college education or college graduate	14.27		
N	722		

Table 2 tabulates mammography screening responses for each of the four domains of health care system distrust. There were no discernible differences in the responses to the question on ever having a mammogram and the four domains of health care system distrust. However, one-year mammography screening rates were lower for respondents who agreed with the distrust questions related to honesty, competence and fidelity. Differences in one-year mammography screening rates were particularly low—and statistically significant at the one percent level ($p<.01$)—for the competence domain. Thirty-one percent of respondents who agreed with the statement that people die every day due to health care system mistakes had a mammogram within the last year compared with 47% of respondents who did not agree or were neutral with this statement ($p<.01$).

Table 2: Tabulation of Health Care System Distrust and Mammography Screening

	Ever had a Mammogram			**Had a Mammogram within the Last Year**		
	No	**Yes**	**X^2 Test**	**No**	**Yes**	**X^2 Test**
Health Care System Distrust	**Row %**			**Row %**		
Medical experiments can be done on me without me knowing about it						
No	12.93	87.07		52.59	47.41	
Yes	14.93	85.07		56.22	43.78	
			0.31			0.52
People can get access to my medical records without my approval						
No	10.37	89.63		59.76	40.24	
Yes	15.16	84.84		53.60	46.40	
			0.12			1.92
People die every day because of mistakes by the health care system						
No	14.24	85.76		53.40	46.60	
Yes	16.16	83.84		68.69	31.31	
			0.61			8.08**
The health care system cares more about holding costs down than it does about doing what is needed for my health						
No	14.50	85.50		54.86	45.14	
Yes	13.58	86.42		56.17	43.83	
			0.09			0.09

* $p < 0.05$, ** $p < 0.01$

Table 3 reports the unadjusted and adjusted results of logistic regression models for ever having mammography screening and having a mammogram within the last year. Unadjusted results included only the four health care system distrust questions/domains whereas adjusted results included all the other variables presented in the Methods section above. Health care system distrust dimensions did not

seem to be related to reports of ever having a mammogram in both unadjusted and adjusted logistic regression models. However, distrust related to honesty ("Medical experiments can be done on me without me knowing about it"; OR=0.61; 95% CI=0.38-0.98) and competence ("People die every day because of mistakes by the health care system"; OR=0.57; 95% CI=0.35-0.93) was significantly related to lower one-year mammography screening in the adjusted logistic regression model.

Table 3: Logistic Regression Results: Mammography Screening

	Ever had a Mammogram		**Had a Mammogram within the Last Year**	
	Unadjusted Odds Ratio [95% CI]	**Adjusted Odds Ratio [95% CI]**	**Unadjusted Odds Ratio [95% CI]**	**Adjusted Odds Ratio [95% CI]**
Medical experiments can be done on me without me knowing about it	1.03 [0.54-1.96]	0.94 [0.49-1.81]	0.74 [0.48-1.16]	0.61* [0.38-0.98]
People can get access to my medical records without my approval	0.65 [0.36-1.19]	0.64 [0.35-1.17]	1.43 [0.96-2.13]	1.45 [0.96-2.20]
People die every day because of mistakes by the health care system	0.81 [0.44-1.48]	0.83 [0.45-1.54]	0.53** [0.33-0.85]	0.57* [0.35-0.93]
The health care system cares more about holding costs down than it does about doing what is needed for my health	1.10 [0.63-1.93]	1.07 [0.61-1.88]	1.08 [0.75-1.55]	1.12 [0.76-1.64]
Age*: 50-59 years*		1.79 [0.91-3.52]		0.79 [0.49-1.29]
Age: *60-69 years*		1.56 [0.77-3.18]		0.40** [0.23-0.67]
Age: *70+ years*		1.24 [0.57-2.70]		0.40** [0.23-0.70]
Educational Attainment: *Less than high school*		0.58 [0.24-1.39]		0.71 [0.42-1.22]
Educational Attainment: *High school*		0.65 [0.25-1.68]		1.17 [0.67-2.07]
Marital Status: *Married*		1.16 [0.70-1.91]		1.20 [0.84-1.72]
Household Income: *Less than or equal to $10,000 per year*		1.45 [0.83-2.53]		1.17 [0.78-1.74]
Health Insurance Coverage: *Uninsured*		0.56* [0.32-0.99]		0.39** [0.25-0.60]
U.S. Acculturation Level: *Lower (SASH score below 3)*		0.79 [0.37-1.68]		1.41 [0.87-2.29]

* $p < 0.05$, ** $p < 0.01$

In adjusted regression models, respondents ages 60-69 and ages 70 or more had lower odds of having a mammogram within the last year compared to all other respondents ((OR=0.40; 95% CI=0.23-0.67) and (OR=0.40; 95% CI=0.23-0.70), respectively). Compared to insured respondents, uninsured survey participants had much lower odds of ever having a mammogram (OR=0.56; 95% CI=0.32-0.99) or having had a mammogram within the last year (OR=0.39; 95% CI=0.25-0.60). Educational attainment, marital status and US acculturation were not significantly related to mammography screening behavior and adherence in adjusted regression models. Additional analyses were conducted to test the sensitivity of the results. First, alternative questions which have been identified in previous research to capture the four domains of health care system distrust were also considered (e.g., "When they take my blood, they do tests they don't tell me about", "If a mistake were made in my health care, the health care system would try to hide it from

me" and "Some medicines have things in them that they don't tell you about" for honesty, "My medical records are kept private" for confidentiality, "I receive high-quality medical care from the health care system" for competence, and "The health care system puts my medical needs above all other considerations when treating my medical problems" for fidelity).[11] The alternative questions for honesty, competence and fidelity were deemed to be endogenous compared to the measure utilized in the results reported above. Moreover, the regression results were estimated with the alternative confidentiality questions but the main findings remained qualitatively the same.

The level of functional health literacy of survey respondents was also considered given that this is likely to be an important factor affecting mammography screening. Poor health literacy is likely to reduce basic understanding of both oral and written information related to breast cancer screening recommendations. Health literacy was measured in the survey using the Short Test of Functional Health Literacy (STOFHLA).[23] Inadequate or marginal health literacy was found to be an important determinant of mammography screening, but the main results related to the honesty and competence domains of health care system distrust remained largely the same even after adjusting for this important factor.

Breast cancer screening adherence for Mexican American women in the LRGV of South Texas is very low, with a one-year mammography screening rate of only 44%. Although lack of health insurance coverage was a key factor explaining lower mammography uptake and adherence in this Hispanic subpopulation, health care system distrust was also identified as an important determinant of low breast cancer screening adherence for this ethnic group.

Distrust in the health care system goes beyond the absence of trust—it also encompasses the notion that these providers and institutions may behave in ways detrimental to the well-being of health care service users.[11,24] As in other settings, health care trust is difficult to earn, and easy to lose.[16] This asymmetry is important because if trust is important to advance health care outcomes, those outcomes may rest in part on very fragile social contracts that are difficult to create and hard to sustain.

We found that two key domains of health care system distrust—honesty and competence—were linked to lower one-year mammography screening rates. More specifically, women who agreed that medical experiments could be done without their knowledge were less likely to report to have had a mammogram within the last year compared to women not agreeing with this statement. Furthermore, women who agreed that people die every day because of mistakes made by the health care system were less likely to report to have had a mammogram within the last year compared to women not agreeing with this statement. These two distrust domains are crucial in that, for instance, it obviously will take a substantial amount of time to change the opinion of a health care user that is distrustful of the honesty and competence of health care providers and institutions. The main policy implication of this result is that building continuing trust in health care providers and institutions is important to encourage the appropriate use of health care services which require a long lasting, trusting relationship between patients and providers—like breast cancer screening. However, trust building has to be coordinated across different health care providers and institutions as honesty and competence are trust dimensions that are more general to the health care system and not necessarily specific to a single provider or institution. The simultaneous importance and fragility of health care system trust requires coordinated and relentless efforts—which is particularly challenging in vulnerable populations but, also, particularly meaningful.

Subtask 1.2

Subtask 1.2 was led by Dr. Pagán and it was completed previously and reported upon in the second quarter report. The paper was accepted for publication in the *Journal of Cancer Education* on 22 April 2011. The coauthors of the study include Drs. Pagán (UTPA/UNTHSC), Brown (UTPA), Asch (Penn), Armstrong (Penn), Bastida (Florida International University) and Guerra (Penn). This paper gave an opportunity to the UTPA researchers to further develop their skills in breast cancer research and functional health literacy. The paper is entitled "Health Literacy and Breast Cancer Screening among Mexican American Women in South Texas."

Achieving appropriate screening rates for breast cancer for the Mexican-origin US population represents a significant opportunity to reduce breast cancer morbidity/mortality for an ethnic group facing many breast cancer screening barriers. Lack of health insurance coverage and income are important barriers to mammography utilization but, nonetheless, screening affordability alone does not explain the limited screening in this population.[4]

Health literacy represents the "the ability to obtain, process, and understand basic health information and services to make appropriate health decisions."[5] Low health literacy has been shown to be associated with a limited health vocabulary and it limits how individuals understand the concept of screening and their awareness of its benefits. For example, participants in focus groups and individual interviews in several studies thought screening was unnecessary if their breasts "looked good" or if they had no symptoms.[25] Compared with women with marginal and adequate literacy, women with low literacy were significantly more likely to have negative attitudes about mammography including that a mammogram would be embarrassing, harmful, or painful, and were also more likely to feel that it would be a lot of trouble to get a mammogram.[25] Limited health literacy also reduces patients' understanding of both oral and written information related to breast cancer screening recommendations and processes, in particular written materials because the average readability level of the available cancer screening literature has been found to be in the 10-11th grade reading level.[26,27] Furthermore, low literacy hinders navigation through a complex health care system, limits an individual's ability to complete health

forms, understand appointment slips, interpret medication instructions accurately, and effectively communicate with their physician.[28] Patients with low or poor health literacy may lack numeracy skills to understand and assess the risks and benefits of mammography screening than patients with better health literacy.[29]

Survey data from the 2003 National Assessment of Adult Literacy (NAAL)—the most recent data available—show that only 12% of the US adult population has a health literacy level deemed as proficient and more than a third (77 million people) have a health literacy level classified as basic or below basic.[5] These adults would have difficulty with tasks such as reading a health pamphlet and explaining why someone should not undergo a test for a health condition/disease, or with understanding the directions in a prescription drug label. Moreover, health literacy varies substantially across racial/ethnic groups and health insurance coverage status. About 65% of Hispanic adults have a basic or below basic health literacy level compared to 57% of non-Hispanic blacks and 28 percent of non-Hispanic whites.[5] About 53% of uninsured adults have a basic or below basic health literacy level compared to 24% of adults with employer-provided health insurance coverage.[5]

In this study we examined the association between functional health literacy and mammography screening behavior and adherence among Hispanic women residing in the Lower Rio Grande Valley of Texas, one of the poorest regions in the US which also is characterized by high uninsurance rates and very low mammography screening rates.[4,12] Previous studies assessing the role of functional health literacy on mammography screening behavior of Latinas have shown that functional health literacy is related to ever having a mammogram but it is not related to key measures related to adherence such as having a mammogram within the last one or two years.[6] Studies which have identified health insurance coverage as the main determinant of breast cancer screening for Latina populations did not explicitly account for functional health literacy as a key factor in breast cancer screening behavior.[4] As such, the primary hypothesis of this study was that inadequate health literacy is independently associated with low mammography uptake and adherence, even after accounting for health insurance coverage status, household income and other demographic and socioeconomic factors.

We interviewed 736 Mexican American women selected at random from a population-based panel study of middle-aged and older Latinos/as residing in the Rio Grande Valley of South Texas (the Border Epidemiologic Study on Aging, BESA). The BESA sample was first interviewed in 1994-1996 (1,089) and participants were selected at random from the Latino population in the Rio Grande Valley. This region of South Texas includes the counties of Cameron, Hidalgo and Starr. The original BESA sample was augmented through additional data collection waves conducted from 1998 to 2006.[17]

The mammography screening module included responses from a random sample of Latinas 40 years of age and older. Face-to-face interviews were conducted in either English or Spanish from January to June 2008. Written informed consent was obtained before interviewing study participants at their home. Survey participants were compensated with a $30 gift card from a local supermarket and interviews were 20 to 30 minutes long. The study protocol was approved by the Institutional Review Boards of the University of Texas-Pan American and the University of North Texas Health Science Center, and reviewed by the U.S. Army Medical Research and Materiel Command's Office of Research Protections, Human Research Protection Office.

Study respondents provided demographic and socioeconomic information as well as answers to questions related to their knowledge, attitudes and behaviors about breast cancer and mammography screening. More specifically, all survey participants were asked a general yes/no question "Have you ever had a mammogram?" Respondents who answered "yes" were then asked "When did you have your last mammogram?" and categorical responses to this question ("Within 1 year", "Between 1 and 2 years", "Between 2 and 3 years", "Between 3 and 5 years" and "More than 5 years") were recoded to create two adherence variables: whether or not the respondent reported a mammogram within the last year and whether or not the respondent had reported a mammogram within the last two years. Respondents with "Don't know" and "No Answer" responses were excluded from the analysis.

Survey participants were also given the Short Test of Functional Health Literacy (STOFHLA) in either English or Spanish.[23] The STOFHLA includes two reading comprehension passages—patient medical instructions for preparing for an x-ray and the rights and responsibilities section of a Medicaid application form. The test includes 36 questions and both the English and Spanish versions of the survey instrument have been validated.[30] Respondents with a STOFHLA score of 23-36 were classified as having adequate functional health literacy while respondents with scores ranging from 0-16 and 17-22 were classified as having inadequate and marginal functional health literacy, respectively.[23]

Table 1 above described the sample of 722 respondents used in the analysis. Almost 86% of respondents reported that they ever had a mammogram done. About 62% said that they had a mammogram within the last two years and 44% stated that they had a mammogram within the last year. More than half the respondents were over 60 years of age. Almost 70% of respondents had less than a high school education. About 58% of respondents were married and 58% had a household income of less than $10,000 a year. A quarter of respondents (27%) had no health insurance coverage and four out of every five respondents (79%) had SASH scores consistent with a relatively low level of US acculturation. Half of all survey participants had inadequate or marginal functional health literacy (STOFHLA) scores (50%) (not shown in Table 1).

Table 4 reports the results of logistic regression models for ever having mammography screening and having a mammogram within the last year (we also estimated models for having a mammogram within the last two years and these results were included in the published article, and discussed below). Unadjusted and adjusted results are reported for all the three mammography screening variables. Unadjusted results only included the variable being considered in the estimated logistic regression model (e.g., only years of age categories were included in the unadjusted odds ratios (OR) reported for the age indicator variables) while adjusted results included all the variables in each estimated logistic regression model. In adjusted regression models, respondents ages 50-69 had higher odds of ever having a mammogram compared to all other respondents ((OR=2.23; 95% CI=1.10-4.51) and (OR=2.36; 95% CI=1.11-5.03) while respondents 60-69 had lower odds of having a mammogram within the last year compared to all other respondents (OR=0.49; 95% CI=0.29-0.84). Educational attainment and marital status were not significantly related to mammography screening behavior and adherence in adjusted regression models. Although high household income was associated with mammography screening behavior and adherence, the ORs become statistically insignificant after adjusting for all the other demographic and socioeconomic variables included in the models. The same result applies to US acculturation level—low acculturation was related to low mammography screening propensity but only in unadjusted logistic regression models. Health insurance coverage was consistently related to the three mammography screening indicators in both unadjusted and adjusted logistic regression models (with uninsured respondents much less likely to ever had a mammogram or to have had a mammogram within the last one or two years, than insured respondents). Adequate functional health literacy was strongly and consistently associated with higher mammography screening uptake and adherence in both unadjusted and adjusted logistic regression models. In adjusted models, those with STOFHLA scores above 22 were more likely to report that they ever had a mammogram (OR=2.92; 95% CI=1.62-5.28), had a mammogram within the last two years (OR=1.70; 95% CI=1.14-2.53) and had a mammogram within the last year (OR=2.30; 95% CI=1.54-3.43).

Table 4: Logistic Regression Results: Mammography Screening

	Ever had a Mammogram		**Had a Mammogram within the Last Year**	
	Unadjusted Odds Ratio [95% CI]	**Adjusted Odds Ratio [95% CI]**	**Unadjusted Odds Ratio [95% CI]**	**Adjusted Odds Ratio [95% CI]**
Age*: 50-59 years*	1.60 [0.83-3.09]	2.23* [1.10-4.51]	0.80 [0.50-1.27]	0.88 [0.54-1.44]
Age: *60-69 years*	1.38 [0.73-2.59]	2.36* [1.11-5.03]	0.43** [0.27-0.69]	0.49** [0.29-0.84]
Age: *70+ years*	1.14 [0.65-2.03]	2.26 [0.98-5.22]	0.49** [0.32-0.76]	0.59 [0.33-1.1]
Educational Attainment: *Less than high school*	0.44* [0.20-0.93]	0.83 [0.33-2.08]	0.51** [0.33-0.78]	0.93 [0.53-1.60]
Educational Attainment: *High school*	0.63 [0.25-1.56]	0.72 [0.28-1.87]	1.09 [0.63-1.9]	1.20 [0.68-2.11]
Marital Status: *Married*	1.27 [0.84-1.93]	1.11 [0.67-1.83]	1.45* [1.07-1.96]	1.20 [0.83-1.71]
Household Income: *Less than or equal to $10,000 per year*	1.77** [1.17-2.70]	1.37 [0.81-2.31]	1.71** [1.26-2.31]	1.10 [0.74-1.62]
Health Insurance Coverage: *Uninsured*	0.56* [0.36-0.87]	0.54* [0.30-0.94]	0.62** [0.44-0.87]	0.38** [0.25-0.60]
U.S. Acculturation Level: *Lower (SASH score below 3)*	0.50* [0.27-0.93]	0.92 [0.43-1.99]	0.65* [0.46-0.94]	1.54 [0.95-2.50]
Functional Health Literacy: *Adequate (STOFHLA score above 22)*	2.31** [1.49-3.56]	2.92** [1.62-5.28]	2.51** [1.86-3.40]	2.30** [1.54-3.43]

* $p < 0.05$, ** $p < 0.01$

Accurate identification of screening barriers is a fundamental step required before interventions to increase mammography utilization among Latinas can be designed and implemented effectively. Considerable attention has been focused on barriers within the health care system—such as inadequate health insurance coverage. And while system-level internal barriers are real and important, more fundamental population factors may have larger effects. We have identified inadequate functional health literacy as an important factor related to mammography uptake and adherence in our study population. One of every two of our Mexican-origin Latina respondents surveyed had STOFHLA scores which place them in the category of having marginal or inadequate health literacy skills. And more than any other factor measured in this study, low health literacy was strongly associated with lower mammography uptake.

Even though the causal directions, pathways and mechanisms of these strong associations are not established by this study, low literacy is such a foundational deficit that it is likely to be at least partly mediating our observations—even if it is partly co-determined by other, more fundamental factors. While we await later studies that might untangle these effects, our results offer some plausible strategies to improving Latina breast cancer screening. Therefore, while increasing health insurance coverage in the South Texas border region will probably increase mammography screening rates in this region of the country substantially, improving health literacy levels may have a larger effect, and one that may sustain welfare benefits beyond health. And while improving literacy is challenging, we can, in the meantime, recognize that health information needs to be provided in ways that are easily understood by everyone.

For example, designing print health materials at appropriate reading levels is necessary to make them accessible to larger segments of the population, but they also need to be continuously redesigned and tested to better match the needs of the intended audience.[5] This is particularly relevant in US-Mexico border communities, which are characterized by rapidly changing population patterns related to immigration. Another promising approach to address health literacy challenges related to breast cancer screening is to use patient navigators (community health workers or promotoras) as this workforce is already embedded in many border communities and they can readily assist low literacy populations in obtaining breast cancer information. Recent studies have shown that the use of community health workers can increase mammography screening and self-efficacy as well as the level of perceived susceptibility and benefits of breast cancer screening in US-Mexico border communities.[31,32] Thus, community health workers not only can help to improve health literacy levels by delivering educational materials but they can also help low literacy populations to effectively access health care services available in local communities.

South Texas border communities have the highest rates of uninsurance in the US and these local health care markets will see disproportionate increases in health insurance coverage rates as a result of the recent health care reform efforts. The development of tailored mammography screening materials and health care system navigating processes for these populations offer a promising opportunity to better meet their needs, particularly of women of screening age which will be participating in new health public and private health insurance coverage programs in this region.

Subtask 1.3

Subtask 1.3 was led by Dr. Hinojosa and the study evaluated the way Mexican American women take family breast cancer history into account when assigning importance to timely mammography screening. This paper was completed and submitted on schedule to the journal *Health Policy* on 25 August 2010. Dr. Hinojosa received a notification in September 2010 that *Health Policy* did not find the paper suitable for their journal given their focus and scope. The paper was revised and then submitted to the *Journal of Health Care for the Poor and Underserved* in September 2010 (the same month). We received a response 03 January 2011 that they decided against proceeding further with the paper. We received comments from three reviewers who gave concrete, useful suggestions on how to improve the focus of the study. One of the reviewers commented that "This is a very important study reporting that an urgent need to the Latinas women by making a public awareness that mammogram[s] and breast self examination[s] are important for detecting breast cancer at earlier stage. They ought to recognize that early detection of small tumor lumps allows immediate medical treatments so that survival of patients can be prolonged. In addition, many survey data covered in this report also indicate that demographic, socioeconomic, education, and other variables affect the concept of necessity of having routine mammograms yearly. Perhaps, the sub-population who didn't view the importance of mammogram shall be further persuaded." Another reviewer commented that "Examining and reporting perceptions about breast cancer screening among Mexican women in the border region is very important." The reviewers also had very specific comments on how to review and improve the focus of the paper. Dr. Hinojosa addressed these comments and revisions and the paper will be resubmitted to a health policy-oriented journal during the summer. The main results are discussed next.

Numerous factors affect the incidence of breast cancer. Among women of different Latin American backgrounds, often referred to as Hispanic women or simply Latinas, heredity is considered an especially important predictor of this health condition.[1] In view of this, perceptions of heredity by these women might directly affect their screening mammography behavior. The purpose of this study is to report findings from a study intended to assess the perception of the importance of screening mammography in a subset of Latinas, Mexican American women, who reside in the border region of Texas. This study specifically identifies how heredity beliefs affect the perceived importance of screening mammography in this cohort. In doing so, the study reveals differences in perceptions of heredity within the same ethnic group and places a renewed spotlight on heredity-centered barriers to cancer screening in a population already heavily burdened by breast disease. The study brings Mexican American women's ideas about breast cancer, heredity, and the need

for mammography into clearer focus by drawing attention to Mexican American women residing in the South Texas-Mexico border region, one of the most impoverished and medically underserved regions of the country.[14]

For many Mexican American women, heredity is a major consideration when assessing breast cancer risk. Together with group-specific beliefs about breast cancer, such as that the disease can be caused by mammography radiation,[2] breastfeeding,[2] and trauma,[3] heredity concerns weigh heavily on the minds of Mexican American women. So pervasive are heredity concerns that many Mexican American women without breast cancer in their family believe that they are unlikely to get cancer, and so avoid or delay mammography screening. In common with Mexican American women, other Latinas often voice their concerns about breast cancer vulnerability in terms of their family disease history,[1] with many fearing that cancer runs in the family; if the mother has it, the daughter may get it.[2] But we find that among Mexican-descent women, in particular, "the belief that heredity causes cancer is the most influential of the physical predetermination beliefs across women of various levels of acculturation and education."[12] Conversely, those women without a family history of breast cancer feel they are less susceptible to it, and are less likely to screen for it.[12] An important outcome of this is that screening mammography has had—and continues to have—a difficult time being fully accepted by Mexican American women.

This situation raises concerns about the degree to which Mexican Americans' perceptions of heredity affect their willingness to get a mammogram. What many of these women do not take into account is that in 90% of its incidence, breast cancer is not associated with genetics, but with other factors.[13] Only a small proportion, some ten percent, of breast cancer cases appear linked to genetics.[1, 27] Still, genetics looms large as a breast cancer determinant among Mexican American women, as we see also among other Latinas.

Research on breast cancer among Latinas in general has identified many such problematic perceptions of heredity and vulnerability among these women. Misdirected concerns about heredity and vulnerability have been found, for instance, to be associated not only with the underuse of screening among Latinas in general, but with medically indefensible screening. Luquis and Villanueva Cruz, for example, reported how two-fifths of the Latinas they sampled said that mammograms are necessary for women in their thirties.[2] Some Latinas even said women need mammograms in their twenties, especially after having a baby. Only half the Latinas sampled said that mammograms are needed yearly after age forty.[2] Moreover, heredity-centered thinking can encourage fear-driven decision making, and may exacerbate feelings of futility among women already worried about their family vulnerability. Ultimately, Latinas may avoid screening because they fear they will get unwanted results. Researchers note a certain resignation among Latinas about breast cancer, especially when the disease is considered a form of divine punishment.[5] For these reasons, many Latinas, including Mexican American women, prefer not knowing whether or not they have the disease.[3,5]

Latina perceptions of heredity and vulnerability have operated within a framework of uneven and delayed screening encompassing at least the last two decades. The 1990s, for example, saw relatively lower screening rates among Latinas than among white women. By the end of the decade, though, Latinas had grown more accepting of mammograms, and their screening rates increased more rapidly than those of white women.[4] With the increased screening, the rate of early-stage breast cancer detection among Latinas increased.[4] This occurred in the late 1990s as breast cancer mortality decreased for women in general. But a significant diagnostic issue became apparent among Latinas: while new breast cancer cases appeared less often among Latinas than among whites, tumors were being detected at more advanced stages among Latinas than among white or black women.[5,6] Unsettling as this is, however, this problem has not been unique to Latinas. Being an ethnic/racial minority of any background, and being uninsured, elevates a woman's risk of being diagnosed with late-stage disease, compared with white or insured women.[7] Compounding this picture is their determination that uninsured women are only half as likely as insured women to have had a biopsy.[7] These findings, together with the lower five-year breast cancer survival rate of Hispanics (77.6%) than for non-Hispanic whites (81.5%),[1] serve as a stark reminders that Hispanic women have an overall higher likelihood of dying from breast cancer than white women.[8]

Efforts to explain limited Latina use of mammography have noted that many Latinas distrust body scans,[10] worry about immodest physical exposure during exams, and exhibit a curative rather than a preventive orientation to disease.[5] Of particular interest is the finding that, among Latinas of different backgrounds, Mexican American women are the most insulated from breast cancer information.[1] Mexican American women reported that breast cancer was a topic of great secrecy, even in the family. Factors like these likely translate into Mexican American women receiving fewer breast screenings than necessary. This is especially worrisome because breast cancer is most treatable when it is too small to be detected with a breast self examination, that is, when a mammogram <u>can</u> detect it.[11] The uneven acceptance of mammography among Mexican American women thus deprives many women of an essential diagnostic opportunity. It also points to how some women assess personal risk in medically unjustified ways, such as those centering on family disease history.

This study focused on breast cancer heredity perceptions as well as on demographic and socioeconomic questions. All survey participants responded to the following question on heredity: "When do you think it is especially important to get a mammogram?" For this question they had the choice of answering, a) when there is breast cancer is in the family, b) when there is no breast cancer in the family, c) whether or not there is breast cancer in the family, d) it is not important to get a mammogram, or e) do not know. Responses to this question were evaluated by age groups to assess differences across age categories.

Logistic regression was used to assess the socioeconomic and demographic factors related to the perceived importance of having a mammogram when there is breast cancer in the family. The variables included in the analysis were years of age (40-49, 50-59, 60-69, and 70 and above years of age), educational attainment (less than high school, high school, and some college education or college graduate), marital status (married vs. not married), household income (more than $10,000 vs. less than $10,000 per year), health insurance coverage (insured vs. uninsured), and U.S. acculturation level (lower vs. higher). Acculturation was measured using the Short Acculturation Scale for Hispanics (SASH), a validated scale on acculturation focusing on language use, media, and ethnic social relations that has been widely used in health research.[16, 17, 18]

The survey instrument captured demographic and socioeconomic information of the participants, as well as information on their knowledge, beliefs, attitudes, and behaviors concerning mammography and breast self-examination. Table 1 reported the descriptive statistics of the sample used in the analysis. The discussion on this sample was included above in that table. As for the questions specific to this study, the vast majority of respondents (n=563, 76.49%) answered that it was especially important to get a mammogram whether or not there is breast cancer in the family, indicating prima facie compliance with screening recommendations. However, the next largest cluster of responses (n=117, 15.90%) centered on the first choice, indicating that this subset of women believed it was especially important to get a mammogram when there is breast cancer in the family. The remaining responses (n=56, 7.61%) totaled fewer than half the size of this cluster.

Initial review of the data suggests that over three-quarters of respondents felt that undergoing mammography screening was important regardless of family breast cancer history, and that a very high proportion of respondents (n=687, 93.3%) found it important to undergo mammography screening in general. But this study also points to a serious area of concern. If 15.9% of respondents report that a mammogram is most important when there is breast cancer in the family, this means that about one out of six Mexican American women might avoid getting screened because she believes that, one, having a positive family history of breast cancer is the most important determinant of personal breast cancer risk and, two, if there is no breast cancer in her family, she is not at risk for the disease. These figures suggest that many Mexican American women feel that most breast cancers are caused by heredity, and that cursory knowledge of family disease history can guide one in making screening decisions. For this subset of women, genetics is the only risk factor worth considering, and acting upon.

Table 5 tabulates responses by age and perceived importance of having a mammogram. This analysis reveals other dimensions of the problem. Older women are increasingly more likely to think that they should get a mammogram when breast cancer is in the family. Concerns about heredity and breast cancer risk are especially heightened in this group. This is especially troubling because Latinas aged forty to sixty already seek mammograms at lower rates than women of all other ethnicities in the United States.[21]

Table 5: Tabulation of Age by Perceived Importance of Having a Mammogram

	Perceived Importance of Having a Mammogram					
	Breast cancer in family	**No breast cancer in family**	**Whether or not breast cancer in family**	**Not important**	**Do not know**	**Total**
Age	**Row % [Column %]**					
40-49 years	10.24 [11.11]	0.00 [0.00]	85.83 [19.36]	0.00 [0.00]	3.94 [12.50]	100 [17.96]
50-59 years	16.28 [23.93]	0.58 [20.00]	76.65 [24.33]	1.16 [18.18]	2.33 [10.00]	100 [23.37]
60-69 years	18.48 [29.06]	1.09 [40.00]	72.28 [23.62]	2.17 [36.36]	5.98 [27.50]	100 [25.00]
70+ years	16.60 [35.90]	0.79 [40.00]	72.73 [32.68]	1.98 [45.45]	7.91 [50.00]	100 [34.38]
Total	15.90 [100]	0.68 [100]	76.49 [100]	1.49 [100]	5.43 [100]	100 [100]

Table 6 reports the results of logistic regression analyses of the perceived importance of having a mammogram when there is breast cancer in the family (compared to all other responses, including responses tied to breast cancer being present or absent in the family). Two sets of results are presented—unadjusted and adjusted odds ratios (OR) (i.e., results adjusted for all other variables considered in

the model). Age was associated with the perceived importance of having a mammogram when there is breast cancer in the family (as reported in Table 5). Respondents with less than a high school education were much more likely to report that it was important to have a mammogram when there is breast cancer in the family compared to all other respondents (OR=2.89, 95% CI=1.26-6.68). Respondents with lower U.S. acculturation levels were less likely to report that it was important to have a mammogram when there is breast cancer in the family compared to respondents with higher U.S. acculturation levels (OR=0.44, 95%CI=0.23-0.85). Marital status, household income level, and health insurance coverage status were not statistically significant in the unadjusted and adjusted logistic regression models.

Table 6: Logistic Regression Results: Perceived Importance of Having a Mammogram (When there is Breast Cancer in the Family vs. Otherwise)

	Unadjusted Odds Ratio [95% CI]	**Adjusted Odds Ratio [95% CI]**
Age		
50-59 years	1.71 [0.85-3.44]	1.62 [0.79-3.31]
60-69 years	1.99 [1.00-3.94]	1.92 [0.92-4.01]
70+ years	1.75 [0.90-3.39]	1.75 [0.79-3.91]
Educational Attainment		
Less than high school	2.23 [1.10-4.54]	2.90 [1.26-6.68]
High school	1.59 [0.67-3.76]	1.67 [0.69-4.04]
Marital Status		
Married	0.87 [0.59-1.30]	1.00 [0.62-1.60]
Household Income		
Less than or equal to $10,000 per year	0.81 [0.52-1.26]	0.93 [0.54-1.60]
Health insurance coverage	1.11	1.30
Uninsured	[0.71-1.72]	[0.75-2.23]
U.S. acculturation level		
Lower (SASH score below 3)	0.87 [0.54-1.40]	0.44 [0.23-0.85]
N	736	

This study provides data on how one group of Mexican American women perceives heredity in relation to breast cancer risk and screening. The study identified the way heredity beliefs affect how these women residing in the border region of Texas perceive the importance of screening mammography. While many Mexican American women consider family breast cancer history to be an important determinant of the disease, some Mexican American women attribute considerably more causal significance to it. The finding that about one out of six women felt that screening mammography is most important when there is breast cancer in the family speaks to how many Mexican American women may be enacting screening avoidance behaviors founded on a limited understanding of the role of heredity in breast cancer. By sizing up their personal breast cancer risk in this way, these women might not only be missing out on valuable diagnostic opportunities, but compounding the already heavy breast cancer burden shouldered by Mexican American women**.** This is cause for concern because with the projected steady growth of the overall Latino—and mostly of Mexican descent—population in the US, the absolute number of women who avoid screening mammography on the basis of a negative family breast cancer history is likely to increase.

The evidence suggests that many Mexican American women, especially older ones, harbor the perception that personal family disease history is a very important, and actionable, factor to consider when making screening mammography decisions. Together with the

finding that this outlook is especially pronounced among Mexican American women of lower educational levels, this study suggests that their perceptions about family breast cancer history and personal breast cancer risk are not only a partial reflection of these women's ages, but of their literacy and income characteristics. As research on African American women has found, having limited literacy and limited knowledge about screening mammography can contribute to low-income women underutilizing screening mammography.[29] Mexican American women are already very shielded from breast cancer information and, as this study found, their income levels are extremely low, with 58% of the sample having an annual household income of under $10,000. This may increase the likelihood that many Mexican American women will avoid screening or delay it to well beyond the recommended age of forty. The underuse of mammography is also signaled by a recent study of Mexican American women with breast cancer, that found that 68% of the women in the study discovered their cancer by breast self-examination, while only 22% were diagnosed by screening mammography.[38] It is worth restating that by the time a tumor can be palpated, it may be less treatable than it would be had it been detected earlier by mammography.[11] Delaying or underusing mammography in this manner may increase the already large proportion of late stage breast cancer tumors diagnosed in Mexican American women.

One finding in this study speaks to the possibility that changing US acculturation levels may impact how women think about heredity when assessing their personal breast cancer risk. The study found higher US acculturation levels to be associated with an overemphasis on the connection between heredity and breast cancer. Women with a reported SASH score of 3.0 or higher were more likely to report that mammography is necessary when breast cancer is in the family. This finding may suggest that Mexican-descent women who are either US-born or who have lived in the US longer (who have higher acculturation scores) are more aware of the very factor of heredity and so associate breast cancer more with it. Conversely, women who are more likely to be Mexico-born or who have lived in the US for fewer years may not be as aware of the heredity dimension of breast cancer and so underemphasize it. Further research is needed to verify this, but it is worth bearing in mind that acculturation may occur unevenly within a given population.[32] Some original cultural features of the group may be more resilient than others, [39] just as some members of the group may retain more of their original cultural features. As a result, a range of factors may account for the differences in heredity beliefs noted above.

While more research on Mexican American women and breast cancer is urgently needed[35, 38], current studies on Latinas in general do offer insights into the health predicament of Mexican-descent women. Still, research drawn from the broader Latina population is most useful when coupled to Mexican American-specific findings. To the extent that research can explain how heredity perceptions and beliefs translate into screening, it may go a long way toward elucidating, and reversing, the rocky acceptance of screening mammography by Mexican American women.

One way to redress the underuse of diagnostic screening by Mexican American women is to direct specially-designed messages toward women who feel that without breast cancer in their family, they are not susceptible to the disease. By broadening the appeal of mammograms to women who believe breast cancer is primarily caused by heredity, more of this group's screening practices might be brought into line with national recommendations. For this outreach to have the intended effects, though, the outreach team should know the target group. Different Latina groups and subgroups feature sizable variations in acculturation, health insurance coverage, mortality, and literacy.[37] And within each group, different age sets constitute finer subsets, still. Building effective outreach messages will require knowing not only indicators like these, though, but knowing Mexican American ways of understanding normative health states, and Mexican American ways of sizing up health risk in the absence of disease symptoms. It will also rest on using clear and encouraging language to remind women that heredity is implicated in only a fraction of breast cancer cases.

Outreach messages must be attentive to several things. They should contain clear information about the limited role of heredity in breast cancer. They should be restrained in tone, seeking to raise awareness, not anxiety. In addition, they should be employed as part of an overall effort originating from sources of information that Mexican American women trust. For this reason it is worth exploring further how physicians,[5,8, 39] held in high esteem by Mexican American women, and community health promoters[1,28] could assume a more central role in breast cancer screening outreach and follow-up.

Subtask 1.4

Subtask 1.4 involved the submission of these three manuscripts to peer-reviewed journals. The health literacy paper was accepted in the *Journal of Cancer Education* and the health care system distrust paper is under review in the *American Journal of Preventive Medicine*. The family breast cancer history paper will be resubmitted to a health policy-oriented journal.

Subtask 2.1

Subtask 2.1 involved the funding of breast cancer research through the South Texas Border Health Disparities Center. During the Fall 2010 Semester Dr. Dejun Su, Director of the South Texas Border Health Disparities Center at the University of Texas-Pan American, included breast cancer screening in the Call for Proposals by the Health Disparities Center that went out in September 2010. The eligibility criteria in the Request for Proposals were the following: "To qualify for a research grant through the South Texas Border Health Disparities Center, applicants must meet the following criteria: (i) Applicants' primary affiliation must be with The University of Texas-Pan American; (ii) Proposed research must focus on health and health care access disparities. The Center is particularly

interested in research focusing on health disparities along the U.S.-Mexico border region; (iii) The Center is also interested in developing expertise in breast cancer research at UTPA, with a focus on cancer control and prevention. More specifically, the Center would like to fund one research proposal on barriers to breast cancer screening, particularly among Latinas in the U.S.-Mexico border region. The funding is intended to generate data and results that would allow UTPA investigators to submit competitive breast cancer research proposals to external funding sources such as the Department of Defense's Breast Cancer Research Program, the Centers for Disease Control and Prevention, the National Cancer Institute, and the Cancer Prevention and Research Institute of Texas; and (iv) Previous recipients of STBHDC grants are eligible to apply again. Continuation of previously funded projects is possible if the applicant can justify the need and provide evidence that the project is making solid progress towards a grant submission this semester." The full Call for Proposals can be accessed here: https://portal.utpa.edu/portal/page/portal/utpa_main/daa_home/stbhdc_home/stbhdc_imagesfiles/STBHDC_RFP_2010.pdf. Criterion number (iii) specifically targets an interest in developing breast cancer research focusing on cancer control and prevention particularly as it relates to Latinas in the U.S.-Mexico border region.

This subtask was completed ahead of schedule (1 March 2011) because the Call for Proposals by the Center went out earlier than originally expected. Two cancer research proposals were received—one was recommended for funding pending a carryover request of funds for the South Texas Border Health Disparities Center and the second proposal was not recommended for funding. Both teams of investigators received the comments from the reviewers so that they can improve their proposals and research design (see Appendix for the abstracts of these studies).

Subtask 2.2

Subtask 2.2 involved the planning and submission of a grant proposal on breast cancer research to continue collaborative work between UTPA and Penn. An R21 grant application was submitted to the National Cancer Institute 17 May 2011 (grants.gov number GRANT10870487). Drs. Brown and Pagán are the principal investigators of this proposed study. About one of every eight women in the US will develop breast cancer in their lifetime and there is evidence that early detection through mammography screening can lead to reduced mortality from breast cancer. Although studies have shown that health literacy and numeracy are associated with the ability of individuals to understand medical information and with cancer screening knowledge, the evidence linking these two important constructs to breast cancer screening uptake and adherence is weak, and the causal pathways by which health literacy and numeracy may impact breast cancer uptake and adherence are not well understood. The long-term goal of this grant submission is to reduce the incidence of breast cancer—and its associated disparities and costs—by understanding the role of health literacy and numeracy in breast cancer screening uptake and adherence, and by developing appropriate evidence-based interventions. The objective of the proposal is to assess the role of health literacy and numeracy on breast cancer screening uptake and adherence using a novel modeling approach—a recursive, simultaneous-equation system linking health literacy and numeracy, personal perceptions, and screening uptake/adherence estimated using a conditional mixed process. The central hypothesis of the proposed research is that health literacy and numeracy may be related to breast cancer screening uptake and adherence through perceived rather than actual susceptibility, barriers, benefits, and knowledge about breast cancer. The specific aims of this project are to develop and estimate a structural model which links health literacy and numeracy, perceived breast cancer susceptibility, benefits, barriers, knowledge, and mammography uptake and adherence, assess structural differences in the model across different demographic and socioeconomic groups, and evaluate the predicted effect of improving health literacy and numeracy on perceptions and mammography uptake and adherence. The study will be conducted using a population-based sample of 2,000 women of screening age (40+ years of age) recruited from a national panel of about 50,000 participants selected using probability telephone and address-based recruitment methods. The findings from this research have the potential to identify policy levers that can be used to appropriately design breast cancer screening interventions and reduce health disparities across different demographic and socioeconomic groups.

Subtasks 3.1 and 3.2

Subtasks 3.1 and 3.2 called for continued technical support and mentoring from Penn investigators and their integration in research activities at UTPA under collaborative research work. This has been a continuing activity during the life of the grant as reflected in all the manuscripts completed and/or published, as well as in the grant application to the National Cancer Institute resulting directly from this HBCU/MI Partnership Training Award.

KEY RESEARCH ACCOMPLISHMENTS

- Two important domains of health care system distrust—honesty and competence—were linked to lower one-year mammography screening rates in a sample of Mexican American women of screening age residing in South Texas. Women who agreed that medical experiments could be done without their knowledge were less likely to report to have had a mammogram within the last year compared to women not agreeing with this statement. Also, women who agreed that people die every day because of mistakes made by the health care system were less likely to report to have had a mammogram within the last year compared to women not agreeing with this statement.

- Identified inadequate functional health literacy as an important factor related to mammography uptake and adherence in a sample of Mexican American women of screening age residing in South Texas. One of every two Mexican-origin Latina respondents surveyed had health literacy scores which place them in the category of having marginal or inadequate health literacy skills.

- Identified the way heredity beliefs affect how women residing in the border region of Texas perceive the importance of screening mammography. While many Mexican American women consider family breast cancer history to be an important determinant of the disease, some Mexican American women attribute considerably more causal significance to it. One out of six women felt that screening mammography is most important when there is breast cancer in the family; thus, many Mexican American women may be enacting screening avoidance behaviors founded on a limited understanding of the role of heredity in breast cancer.

- Found that women ages 40 to 69 living in communities with high uninsurance were substantially less likely to undergo mammography, whether or not they have health insurance coverage themselves. These results are consistent with the view that the negative impact of uninsurance extends to everyone in the community regardless of individual health insurance status.

- Found that physicians who perceived an effect of guidelines on their practice were almost twice as likely to exhibit screening prostate-specific antigen (PSA) practice variability, whereas physicians who did not perceive an effect of guidelines on their practice were more likely to be consistent PSA screeners or consistent PSA nonscreeners.

- Analyzed how elderly and near elderly adults assessed hypothetical end-of-life medical treatment choices under different cancer surviving probabilities and out-of-pocket treatment costs. Elderly and near elderly adults would recommend treatment when it was financed by Medicare than by the patient's own savings, and when it had a 60% rather than a 20% survival probability. Black and male respondents were more likely than white and female respondents to recommend treatment regardless of survival probability or payment source.

- Assessed the relative importance of contributing factors to gaps in awareness of genetic testing for cancer risk across racial and ethnic groups. About 48% of non-Hispanic whites had heard about genetic testing, followed by 31% of blacks, 28% of Asians, and 19% of Hispanics. Education and nativity/length of residency in the U.S. explained 26% and 30% of the gap between whites and Hispanics, respectively. Education accounted for 22% of the white– black gap, with residential region explaining another 11%. Nativity/length of residency in the U.S. explained 51% of the white–Asian gap.

REPORTABLE OUTCOMES

Manuscripts Published

Pagán, José A, Dejun Su, Lifeng Li, Katrina Armstrong and David A. Asch. (2010). "Racial and Ethnic Disparities in Awareness of Genetic Testing for Cancer Risk." *American Journal of Preventive Medicine*, **37**(6), 524-530.

Alley D.E., Soldo B.J., Pagán J.A., McCabe J., deBlois M., Field S.H., Asch D.A. & Cannuscio C. (2009). Material resources and population health: Disadvantages in health care, housing, and food among adults over 50. *American Journal of Public Health*, 99(S3), S693-S701.

Pagán, José A., David A. Asch, Cynthia J. Brown, Carmen E. Guerra and Katrina Armstrong. (2008). "Lack of Community Insurance and Mammography Screening Rates among Insured and Uninsured Women," *Journal of Clinical Oncology*, **26**(11), 1865-1870.

Chao, Li-Wei, José A. Pagán and Beth J. Soldo. (2008). "End-of-Life Medical Treatment Choices: Do Survival Chances and Out-of-Pocket Costs Matter?" *Medical Decision Making*, **28**(4), 511-523.

Guerra, Carmen E., Phyllis A. Gimotty, Judy A. Shea, José A. Pagán, J. Sanford Schwartz and Katrina Armstrong. (2008). "Effect of Guidelines on Primary Care Physician Use of PSA Screening: Results from the Community Tracking Study Physician Survey," *Medical Decision Making*, **28**(5), 681-689.

Manuscript in Press

Pagán, José A, Cynthia J. Brown, David A. Asch, Katrina Armstrong, Elena Bastida and Carmen Guerra. (2011). "Health Literacy and Breast Cancer Screening among Mexican American Women in South Texas," *Journal of Cancer Education*, In Press.

Grant awarded (R24, Agency for Healthcare Research and Quality; Grant Number R24HS017003)

UTPA Health Services Research Initiative
Year: 9/1/2007–8/31/2011
Awarded Amount: $1,460,736
Principal Investigators: Cynthia J. Brown (2009-2011) and José A. Pagán (2007-2009)

Grant submitted (R21, National Cancer Institute, National Institutes of Health)

Health Literacy/Numeracy, Perceptions, and Breast Cancer Screening Uptake/Adherence
Year: 4/1/2012–3/31/2014
Principal Investigators: Cynthia J. Brown and José A. Pagán (NIH Multiple PI Grant Submission)

CONCLUSION

The development of a research and training collaborative partnership between the Institute for Population Health Policy (IPHP) at the University of Texas-Pan American and the Leonard Davis Institute of Health Economics (LDI) at the University of Pennsylvania (Penn) has been very successful during the five years of this project and we have been able to accomplish successfully the three tasks in our Statement of Work. The partnership has allowed UTPA researchers to improve their research skills, particularly in the areas of survey instrument development, design of research protocols, data collection, and manuscript and research proposal writing. The outcomes from this collaboration includes several joint manuscripts, a funded federal grant, the development of other grants with UTPA and Penn investigators, and the collection of data on mammography screening practices among Latinas in US/Mexico border communities. These activities will allow this collaboration to further develop over the next few years. In collaboration with Penn investigators and mentors we have successfully developed a breast cancer research program and the research infrastructure that has enabled several UTPA investigators to submit competitive breast cancer research proposals.

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APPENDICES

Appendix A

Reprints of

Pagán, José A, Dejun Su, Lifeng Li, Katrina Armstrong and David A. Asch. (2010). "Racial and Ethnic Disparities in Awareness of Genetic Testing for Cancer Risk." *American Journal of Preventive Medicine*, **37**(6), 524-530.

Alley D.E., Soldo B.J., Pagán J.A., McCabe J., deBlois M., Field S.H., Asch D.A. & Cannuscio C. (2009). Material resources and population health: Disadvantages in health care, housing, and food among adults over 50. *American Journal of Public Health*, 99(S3), S693-S701.

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Appendix B

Survey Instrument

Appendix C

Abstracts of Studies in Call for Proposals by the South Texas Border Health Disparities Center

Appendix D

Abstracts of Grants Awarded and Submitted

Racial and Ethnic Disparities in Awareness of Genetic Testing for Cancer Risk

José A. Pagán, PhD, Dejun Su, PhD, Lifeng Li, MPH, Katrina Armstrong, MD, MSCE, David A. Asch, MD, MBA

Background: Racial and ethnic disparities in awareness of genetic testing for cancer risk are substantial.

Purpose: This study assesses the relative importance of contributing factors to gaps in awareness of genetic testing for cancer risk across racial and ethnic groups.

Methods: Data from the 2005 National Health Interview Survey (N=25,364) were analyzed in 2009 to evaluate the contribution of demographic factors, SES, health status, nativity/length of residency in the U.S., personal/family history of cancer, and perceived cancer risk to racial and ethnic disparities in genetic testing awareness for cancer risk. The contribution of each factor was assessed using the Fairlie decomposition technique.

Results: About 48% of non-Hispanic whites reported that they had heard about genetic testing, followed by 31% of blacks, 28% of Asians, and 19% of Hispanics. Education and nativity/length of residency in the U.S. explained 26% and 30% of the gap between whites and Hispanics, respectively. Education accounted for 22% of the white–black gap, with residential region explaining another 11%. Nativity/length of residency in the U.S. explained 51% of the white–Asian gap.

Conclusions: The relative importance of factors contributing to racial and ethnic disparities in genetic testing awareness is specific to the particular groups under comparison. Diverse, culturally competent approaches are needed to improve awareness for different racial and ethnic groups.

(Am J Prev Med 2009;37(6):524–530) © 2009 American Journal of Preventive Medicine

Introduction

Genetic testing for cancer susceptibility is becoming more commonplace because of the availability of new tests as well as clinical guidelines for genetic counseling and testing.[1,2] Not all demographic and socioeconomic groups, however, have benefited from the growing use of genetic counseling and testing for cancer susceptibility. In particular, racial and ethnic minorities display considerably less use of genetic counseling and testing for cancer risk than non-Hispanic whites.[3–8]

An important contributing factor to racial and ethnic disparities in the use of genetic tests for cancer susceptibility lies in differential levels of awareness of these tests across racial and ethnic groups. According to the 2000 National Health Interview Survey (NHIS), 49.9% of non-Hispanic whites aged ≥25 years reported having heard of genetic testing for increased cancer risk, compared to 32.9% of African Americans, 20.6% of Hispanics, 28% of Asians, and 32.3% of American Indians.[9]

One explanation for the lower awareness on the part of racial- and ethnic-minority groups is that minorities, particularly Hispanics, are less exposed to health information through the healthcare system partially due to language barriers and acculturation factors. This explanation has been corroborated in other studies suggesting that minority groups who are relatively more acculturated to the U.S.—as indicated by either nativity or English proficiency—are also relatively more likely to be aware of genetic testing for cancer risk.[9–12] Besides language and acculturation, racial and ethnic disparities in genetic testing awareness might also result from differences in education, health insurance status, marital status, health, personal or family history of cancer, or other factors. This study uses survey data from the 2005 NHIS and applies logistic regression models and the Fairlie decomposition technique[13,14] to better un-

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0749-3797/09/$–see front matter
doi:10.1016/j.amepre.2009.07.021

derstand the multiple factors that may contribute to racial and ethnic differences in awareness of genetic testing for cancer risk.

Methods

Data and Sample

This study uses data from the 2005 NHIS, a nationally representative, cross-sectional survey of the civilian noninstitutionalized population in the U.S. The NHIS uses a multistage sampling design and it includes questions on SES and demographic status, health status, health behaviors, and healthcare access and utilization. The 2005 NHIS also contained a Cancer Control Module. The sample included in the analysis contains information on a total of 25,364 respondents aged ≥18 years in 2005 who had no missing data.

Measures

Awareness of genetic testing. In the 2005 NHIS, adults were asked to respond whether they have ever heard of genetic testing for cancer risk (*Have you ever heard of genetic testing to determine if a person is at greater risk of developing cancer?*). *Genetic testing for cancer risk* was defined as "testing your blood to see if you carry genes which may predict a greater chance of developing cancer at some point in your life." Respondents answered *yes* or *no* (*refused* or *don't know* answers were excluded from the analysis).

Independent variables. Several independent variables were incorporated in the analysis to reflect demographic status and SES, acculturation, heath status, healthcare access, cancer history, and perceptions of cancer risk. These variables include age, gender, region of residence, educational attainment, marital status, nativity, length of residency in the U.S., employment status, health insurance coverage status, self-reported health status, personal and family history of cancer, and perceived risk of cancer. Nativity (and length of residency in the U.S.) was used as a proxy of acculturation, which was coded into five categories: (1) U.S.-born, (2) foreign-born and lived in the U.S. for 15 years or longer, (3) foreign-born and lived in the U.S. for 10–15 years, (4) foreign-born and lived in the U.S. for 5–10 years, and (5) foreign-born and lived in the U.S. for less than 5 years. Nativity and length of residency in the U.S. are commonly used measures of acculturation, particularly in studies of the relationship between acculturation and health behaviors.[15–18] A three-category variable was created to measure the perceived risk of getting cancer: (1) more likely to get cancer, (2) about as likely to get cancer, and (3) less likely to get cancer.

Data analysis. All statistical analyses in this study were conducted in 2009 using Stata 10.1 software. The analyses took into account the sampling design of the 2005 NHIS (clustering, stratification, and oversampling of Hispanics and African Americans) using the svy procedures in Stata. The percentage distribution of all the variables across racial and ethnic groups was examined first. Logistic regression was then used to assess the relationships between race/ethnicity and awareness of genetic testing with and without adjusting for all other independent variables, respectively. Lastly, the Fairlie decomposition technique was used to quantify and rank the contribution of each variable to explaining the identified racial and ethnic disparities in genetic testing awareness for cancer risk.

Fairlie decomposition. The Fairlie decomposition technique identifies the individual contribution of independent variables to explaining the differences across groups by calculating the change in the average predicted probability resulting from replacing one independent variable at a time for one group while keeping all the other variables constant for the other group.[13,14] Coefficient estimates from a logistic regression based on the sample of the two groups being compared are used to obtain predicted probabilities. Specifically, the following steps were taken to assess the contribution of each of the explanatory variables to racial and ethnic disparities in awareness of genetic testing for cancer susceptibility:

1. The logistic regression coefficients were estimated using the pooled sample of whites and blacks and then each observation in the white and black samples was ranked separately based on the calculated predicted probability of having heard about genetic testing for cancer risk.
2. Given that whites outnumber blacks in the 2005 NHIS sample, a random subsample of whites with a size equal to that of blacks was drawn and then each white observation was matched with the corresponding black observation with the same rank in predicted probability.
3. The contribution to the white–black gap of each single variable in the regression was calculated.
4. Steps 2 and 3 were repeated 1000 times and the average estimated contribution of each variable to the white–black gap in genetic testing awareness was calculated.
5. Steps 1 to 4 were repeated for Hispanics and Asians, respectively, to estimate the contribution of each variable to the white–Hispanic as well as the white–Asian gap in genetic testing awareness.

Results

The 2005 NHIS data revealed substantial racial and ethnic disparities in genetic testing awareness (Table 1). About 48% of white respondents in the 2005 NHIS reported that they had heard about genetic testing, followed by 30.8% of blacks, 27.7% of Asians, and 19% of Hispanics. A very similar percentage distribution was reported by a previous study[9] on awareness of genetic testing using the 2000 NHIS data. These findings suggest that racial and ethnic disparities in genetic testing awareness have remained somewhat stable in the recent past.

The four racial and ethnic groups also differ considerably by region of residence, educational attainment, marital status, health insurance coverage status, nativity and length of residency in the U.S., personal/parental history of cancer, and perceived cancer risk. Of particular salience are the racial and ethnic differences in educational attainment and nativity. Asian Americans in the sample have the highest level of educational attainment, followed by whites, blacks, and Hispanics. Whereas more than 90% of whites and blacks were

born in the U.S., the majority of Hispanics and Asians were born outside the U.S.

Results from Table 2 show the associations between these explanatory variables and the awareness of genetic testing for cancer risk. Factors associated with a higher probability of being aware of genetic testing include being white, older, female, employed, married, in better health, born in the U.S. or residing longer in the U.S. (for immigrants), not residing in the South, being more highly educated, having private health insurance coverage, and having a personal/parental history of cancer. These findings are in anticipated directions and are consistent with what has been reported in previous research based on 2000 NHIS data.[9] Racial and ethnic differences were slightly attenuated after multivariable adjustment, but those differences remained large and significant—suggesting these differences are only partly explained by the other factors.

About 71% of the 29.2% difference in genetic testing awareness between whites and Hispanics (Table 3) can be explained with the variables included in the awareness logistic regression models. Education and nativity/length of residency in the U.S. are the two most important contributing factors. Given that both acculturation and education were associated with a higher level of genetic testing awareness (Table 2), the relatively lower levels of acculturation and education observed in the Hispanic population (Table 1) contribute the most to explaining the white–Hispanic difference in genetic testing awareness.

Similarly, lower educational attainment among African Americans, and regional differences, contributed substantially to the white–black gap in awareness of genetic testing for cancer risk (Table 3). About 48.2% of the 20.5% difference between whites and Asians was explained by the variables included in the awareness logistic regression models. Nativity/length of residency in the U.S. accounted for slightly more than half of this gap. In the 2005 NHIS, only 24.1% of Asians were born in the U.S. compared to 95.6% of whites. This differ-

Table 1. Percentage distribution of all variables used in the analysis by different racial and ethnic groups: NHIS 2005

	Race/ethnicity			
Variables	**White**	**Hispanic**	**African-American**	**Asian**
Heard of genetic testing	48.2	19.0	30.8	27.7
Age (years)				
18–29	19.6	31.5	27.3	27.8
30–39	17.0	27.6	20.1	22.3
40–49	21.4	19.0	21.5	20.4
50–59	18.0	11.7	16.0	15.5
≥60	23.9	10.1	15.1	13.9
Female	51.9	48.7	54.0	48.6
Region of U.S.				
Northeast	19.0	13.2	13.2	16.2
Midwest	30.0	9.4	18.7	12.4
West	17.5	39.9	7.3	46.8
South	33.4	37.5	60.9	24.7
Education				
<High school	10.2	41.2	20.2	9.5
High school graduate	29.4	25.8	32.4	19.2
Some college	30.0	22.1	30.8	22.2
Bachelor's degree or higher	30.3	10.9	16.6	49.2
Marital status				
Married	61.4	57.3	36.5	64.0
Divorced	10.4	8.8	13.1	3.6
Separated	1.5	3.7	4.7	1.2
Single/never married	20.3	27.0	39.2	27.8
Widowed	6.4	3.2	6.4	3.4
Health insurance status				
Private	63.9	42.2	49.2	69.8
Private and public	12.2	1.7	4.4	4.0
Public	12.6	17.1	24.2	10.2
None	11.3	39.1	22.2	16.0
Self-reported health status				
Excellent	31.5	28.4	26.3	36.3
Very good	33.7	29.4	27.7	32.1
Good	24.1	28.9	29.0	25.6
Fair	8.0	10.3	12.7	5.0
Poor	2.7	3.0	4.2	1.0
Employed	66.2	68.8	63.4	65.2
Nativity and length of residency				
U.S.-born	95.6	39.3	91.3	24.1
Foreign-born and stay ≥15 years	2.9	31.3	4.7	41.1
Foreign-born and stay 10–15 years	0.5	8.2	1.1	11.2
Foreign-born and stay 5–10 years	0.5	13.0	2.1	13.0
Foreign-born and stay <5 years	0.4	8.2	0.8	10.5
Personal history of cancer	8.9	2.5	3.4	2.5
Parents' history of cancer	37.0	17.0	22.5	14.4
Perceived cancer risk in self				
More likely to get cancer	14.1	9.5	10.8	5.4
About as likely to get cancer	54.5	54.4	48.7	41.5
Less likely to get cancer	31.4	36.1	40.5	53.1
Number of cases	16,817	4474	3295	720

Source: Estimates based on National Health Interview Survey (NHIS) 2005 (N=25,364)

Table 2. ORs of respondents who reported having heard of genetic testing for cancer risk in 2005

Variables	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Race/ethnicity		
White	1.00	1.00
Hispanic	0.25*** (0.23, 0.28)	0.47*** (0.42, 0.53)
African-American	0.48*** (0.43, 0.53)	0.67*** (0.59, 0.75)
Asian	0.41*** (0.34, 0.50)	0.50*** (0.40, 0.62)
Age (years)		
18–29	—	1.00
30–39	—	1.16** (1.04, 1.29)
40–49	—	1.30*** (1.15, 1.45)
50–59	—	1.51*** (1.33, 1.70)
≥60	—	1.34*** (1.16, 1.55)
Gender		
Male	—	1.00
Female	—	1.46*** (1.36, 1.56)
Region of U.S.		
Northeast	—	1.00
Midwest	—	1.06 (0.94, 1.19)
West	—	1.08 (0.97, 1.21)
South	—	0.81*** (0.73, 0.91)
Education		
<High school	—	1.00
High school graduate	—	1.36*** (1.20, 1.53)
Some college	—	2.36*** (2.09, 2.67)
Bachelor's degree or higher	—	3.69*** (3.27, 4.16)
Marital status		
Married	—	1.00
Divorced	—	0.99 (0.90, 1.09)
Separated	—	1.00 (0.83, 1.22)
Single/never married	—	0.97 (0.88, 1.07)
Widowed	—	0.60*** (0.53, 0.67)
Health insurance status		
Private	—	1.00
Private and public	—	0.84* (0.73, 0.98)
Public	—	0.76*** (0.67, 0.87)
None	—	0.86** (0.77, 0.96)
Self-reported health status		
Excellent	—	1.00
Very good	—	0.95 (0.88, 1.02)
Good	—	0.90* (0.82, 0.98)
Fair	—	0.82** (0.73, 0.93)
Poor	—	0.70*** (0.57, 0.85)
Employment status		
Not employed	—	1.00
Employed	—	1.12* (1.02, 1.22)
Nativity and length of residency		
U.S.-born	—	1.00
Foreign-born and stay ≥15 years	—	0.74*** (0.65, 0.85)
Foreign-born and stay 10–15 years	—	0.48*** (0.35, 0.65)
Foreign-born and stay 5–10 years	—	0.58*** (0.44, 0.75)
Foreign-born and stay <5 years	—	0.48*** (0.34, 0.68)
Personal history of cancer		
No	—	1.00
Yes	—	1.35*** (1.20, 1.53)
Parents' history of cancer		
No	—	1.00
Yes	—	1.27*** (1.18, 1.36)
Perceived cancer risk in self		
More likely to get cancer	—	1.00
About as likely to get cancer	—	0.98 (0.88, 1.09)
Less likely to get cancer	—	0.89* (0.80, 1.00)

Source: Estimates based on National Health Interview Survey 2005 (N=25,364)
*$p<0.05$; **$p<0.01$; ***$p<0.001$

ence in nativity, and the reduced awareness of genetic testing among non-native respondents, explains most of the white–Asian gap in genetic testing awareness. The higher levels of education among Asians compared to whites reduced the white–Asian gap in genetic testing awareness by 14.7%.

Across all three racial- and ethnic-minority groups, a parental history of cancer accounted for a small but significant portion of the white–minority gap in genetic testing awareness. Respondents who reported having a parental history of cancer were more likely to be aware of genetic testing (Table 2), and white respondents were more likely than those from racial- and ethnic-minority groups to report having a parental history of cancer (Table 1).

Discussion

This study reinforces evidence of low levels of awareness and contributes several new findings: First, the results show that awareness of genetic testing for cancer susceptibility is considerably lower among minority U.S. populations than the white population, even after adjusting for a large number of sociodemographic factors that might influence this awareness. Second, the results reveal that education, nativity, and length of residency in the U.S., personal and family cancer history, and geographic region are among the influential factors underlying these majority–minority gaps, findings that could help identify policy remedies to these gaps in awareness.

Table 3. Nonlinear decomposition of the differences between specific racial/ethnic groups and non-Hispanic whites in the percentage of respondents who reported having heard of genetic testing for cancer risk

	Decomposition analysis[a]					
	Hispanic		African-American		Asian	
	Coefficient (SE)	%	Coefficient (SE)	%	Coefficient (SE)	%
White percentage of awareness	0.4822		0.4822		0.4822	
Specific-group percentage of awareness	0.1899		0.3078		0.2772	
Difference	0.2923		0.1744		0.2050	
Contribution of different factors						
Female	0.0028***	1.0	−0.0020***	−1.1	0.0033***	1.6
	(0.0003)		(0.0002)		(0.0004)	
Age	0.0122***	4.2	0.0060***	3.4	0.0069***	3.4
	(0.0021)		(0.0014)		(0.0016)	
Region of U.S.	0.0040	1.4	0.0188***	10.8	−0.0059	−2.9
	(0.0023)		(0.0022)		(0.0030)	
Education	0.0764***	26.1	0.0387***	22.2	−0.0301***	−14.7
	(0.0035)		(0.0017)		(0.0019)	
Marital status	−0.0011	−0.4	0.0072***	4.1	−0.0027***	−1.3
	(0.0010)		(0.0024)		(0.0012)	
Insurance status	0.0061*	2.1	0.0015	0.9	0.0005	0.2
	(0.0028)		(0.0013)		(0.0005)	
Self-reported health status	0.0038***	1.3	0.0056***	3.2	−0.0029***	−1.4
	(0.0007)		(0.0011)		(0.0007)	
Employment status	−0.0001	<0.1	0.0010***	0.6	0.0006**	0.3
	(0.0002)		(0.0003)		(0.0002)	
Nativity and length of residency	0.0877***	30.0	0.0035***	2.0	0.1043***	50.9
	(0.0058)		(0.0009)		(0.0112)	
Personal history of cancer	0.0039***	1.3	0.0039***	2.2	0.0041***	2.0
	(0.0008)		(0.0008)		(0.0009)	
Parents' history of cancer	0.0111***	3.8	0.0082***	4.7	0.0130***	6.3
	(0.0016)		(0.0012)		(0.0020)	
Perceived cancer risk	0.0019***	0.7	0.0027***	1.5	0.0079***	3.9
	(0.0006)		(0.0008)		(0.0020)	
All included variables	0.2088	71.4	0.0951	54.5	0.0988	48.2

Source: Estimates based on National Health Interview Survey 2005

[a]The coefficient estimates for each of the minority groups are the percentage points each variable contributes to the total racial/ethnic gap in genetic testing awareness between whites and the specific minority group studied. Negative percentage points—and percentages—reflect how a factor contributes to narrowing the gap in awareness; positive values imply a widening of the gap in awareness between whites and the specific minority group.

*$p<0.05$; **$p<0.01$; ***$p<0.001$

Third, the importance and likely influence of each of these factors often differ across minority groups, suggesting that policy remedies are unlikely to have uniform population effects and that alternative strategies might be proposed to increase awareness among different racial and ethnic groups. Moreover, 71.4% of the white–Hispanic genetic testing awareness gap could be explained in the decomposition model but only 54.5% of the white–black gap and 48.2% of the white–Asian gap.

The two factors contributing the most to the white–Hispanic gap in genetic testing awareness are education and nativity/length of residency in the U.S. For blacks, the most important factors are education and region of residence and, for Asians, the most important factors are nativity/length of residency in the U.S. and education. However, for Asians, their generally higher educational attainment helps to narrow their awareness gap compared to whites. Perceptions of personal cancer risk and reported rates of parental cancer are higher among non-Hispanic whites than other groups, although these factors explain relatively little of the difference in the genetic testing awareness gap. These differences in risk perceptions may reflect the higher cancer incidence for some cancers among non-Hispanic whites (e.g., breast cancer), but may also reflect the biases of media coverage of cancer cases or cultural differences in discussion of cancer risk within families.

The findings suggest that any single initiative to improve population awareness of genetic testing would itself have uneven effects across different racial and ethnic groups. The influence of nativity and length of residency in the U.S. among Hispanic and Asian populations but not African-American populations might reflect not just the generally larger proportion of African Americans who are native U.S.-born but also reduced information about genetic tests in media using Spanish or Asian languages. It might seem obvious to

say that initiatives targeting minority populations need to present information in culturally relevant media and in native languages, but the results from this study demonstrate just how much of the observed gap might be corrected by these strategies. Tailored approaches to cancer risk communication have achieved success in general,[19] but the best level of customization (e.g., to the individual or social group) and the most specific effective tactics to use are not as well understood.[20]

Similarly, although many social scientists have reflected on racial and ethnic differences in educational attainment and the health and healthcare effects of those differences, this study reminds us just how powerful those effects are. Genetic susceptibility tests for cancer risk represent a new frontier in the personalization of approaches to cancer control. But reaching these frontiers, and helping everyone reach them, will depend on improvements in basic elements of the social infrastructure.[21] The findings demonstrate that non-Hispanic whites perceive greater parental and personal cancer risk than other population subsegments, and these risk perceptions are no doubt products of complex social forces.

Previous findings have documented the importance of awareness of genetic testing for cancer risk in actual use of the tests.[9–11] On the basis of interviews of 622 adults from the state of New York, Bosompra et al.[22] found that being aware of genetic-susceptibility testing for cancer risk was associated with a greater willingness to pay for those services. Despite these findings, it should be noted that improving awareness of genetic testing of racial and ethnic minorities is perhaps only the initial step to reduce racial and ethnic disparities in the use of these testing services. The extant disparities in education, income, health insurance coverage, and community healthcare resources across racial and ethnic groups imply a considerable differential capacity of these groups to transform awareness to actual utilization of genetic testing services when needed.

This study has several limitations. Many socioeconomic and demographic factors that were included are likely to be related to awareness about genetic testing for cancer risk but there are certainly other factors likely to be related to awareness that were not included given data constraints (e.g., risk aversion, the level of patient–physician communication, and the use of different media sources to obtain health information). The analyses were also limited to the major racial- and ethnic-minority groups, although substantial heterogeneity within groups exists (e.g., Asian and Hispanic subgroups). Moreover, awareness of genetic tests for specific types of cancer with different prevalence rates across racial and ethnic groups should influence testing awareness across these same groups. Despite these limitations, the findings from this study underscore the need to increase awareness of new approaches to cancer risk assessment—a need that grows as new opportunities develop for the personalized application of such risk information. This need is great across the population but is greater among certain groups than others, and for different reasons.

Supported by the Agency for Healthcare Research and Quality (Grant R24HS017003); the CDC (Grant H75DP001812-01); and the Department of Defense Breast Cancer Research Program (Grant W81XWH-06-1-0334). Views and opinions of, and endorsements by, the authors do not reflect those of the Agency for Healthcare Research and Quality, the CDC, the U.S. Army, or the Department of Defense.

No financial disclosures were reported by the authors of this paper.

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Material Resources and Population Health: Disadvantages in Health Care, Housing, and Food Among Adults Over 50 Years of Age

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Objectives. We examined associations between material resources and late-life declines in health.

Methods. We used logistic regression to estimate the odds of declines in self-rated health and incident walking limitations associated with material disadvantages in a prospective panel representative of US adults aged 51 years and older (N = 15 441).

Results. Disadvantages in health care (odds ratio [OR] = 1.39; 95% confidence interval [CI] = 1.23, 1.58), food (OR = 1.69; 95% CI = 1.29, 2.22), and housing (OR = 1.20; 95% CI = 1.07, 1.35) were independently associated with declines in self-rated health, whereas only health care (OR = 1.43; 95% CI = 1.29, 1.58) and food (OR = 1.64; 95% CI = 1.31, 2.05) disadvantage predicted incident walking limitations. Participants experiencing multiple material disadvantages were particularly susceptible to worsening health and functional decline. These effects were sustained after we controlled for numerous covariates, including baseline health status and comorbidities. The relations between health declines and non-Hispanic Black race/ethnicity, poverty, marital status, and education were attenuated or eliminated after we controlled for material disadvantage.

Conclusions. Material disadvantages, which are highly policy relevant, appear related to health in ways not captured by education and poverty. Policies to improve health should address a range of basic human needs, rather than health care alone. (*Am J Public Health.* 2009;99:S693–S701. doi:10.2105/AJPH.2009.161877)

The past century has witnessed tremendous advances in medical care and technology, along with gains in life expectancy. Yet, these gains in life expectancy have been unequally distributed and have come to a halt for some disadvantaged groups of Americans.[1] Throughout the life course, poor persons fare worse than higher-income individuals on key health indicators. The poor have lower self-rated health, a higher prevalence of chronic conditions, and higher mortality.[2,3] Health disparities by race/ethnicity appear similarly entrenched.[3,4]

The association between socioeconomic status (SES) and health continues into old age and is evident across the income gradient.[5,6] Higher SES, measured in terms of education, income, or occupational prestige, is associated with decreased mortality among persons aged 65 years and older,[7] whereas lower levels of education, income, and occupation contribute to higher levels of morbidity and mortality in older individuals.[5,7,8] The life-course model posits that accumulated disadvantage can contribute to health status in old age.[5,9] The socioeconomic gradient in health persists in old age despite participation in Medicare, which provides nearly universal health insurance coverage.[5,10] Further improvements in population health will require attention to factors in addition to health care that drive health disparities.[11,12]

Researchers have called for better measurement of characteristics associated with SES other than income,[13,14] including direct measurement of material resources.[15] Material resources, the goods and services that income leverages, have been proposed as critical factors in determining population health, and unequal distribution of these resources may contribute to health disparities.[16,17] Unmet needs related to health care, food, and housing are interrelated indicators of material hardship,[15] but only a few cross-sectional studies have simultaneously considered how multiple forms of material hardship may relate to health.[15,18–20] Instead, previous research has considered the health effects of individual forms of material disadvantage. Inadequate health insurance is related both to lower use of appropriate health services and to poorer health outcomes.[21–23] Food insecurity is related to higher rates of functional impairment among persons aged 60 years and older[24] and to poorer health.[25,26] Home ownership and other shared household amenities and assets are related to better self-rated health through multiple pathways, including housing conditions and neighborhood environments.[27–30] In the present study, we examined simultaneously the population distribution of these 3 basic human needs—health care, food, and housing—and the later-life health consequences of material disadvantage in these domains. We anticipated that each of these material resources would contribute independently to declines in self-rated health and walking ability, even after we controlled for the effects of standard socioeconomic indicators such as education and poverty.

METHODS

We examined data from the 2004 and 2006 Health and Retirement Study (HRS), which is a nationally representative panel study of Americans aged 51 years and older.[31,32] These 2 HRS waves included a new cohort of participants—the early baby boomers—born from 1948 to 1953. Baby boomers account for a disproportionate share of the US population, and there are important differences in wealth and health between baby boomers and earlier cohorts.[33–35] Spouses or partners of HRS participants were excluded from this analysis if they were less than 51 years of age.

We chose outcome measures to reflect midlife and older individuals' underlying health status. Self-rated health is an important predictor of mortality across age, gender, and racial/ethnic groups.[36–38] Participants reported whether their health was excellent, very good, good, fair, or poor in both 2004 and 2006. Consistent with prior research, a major decline in self-rated health was defined as either a decline from excellent, very good, or good health in 2004 to fair or poor health in 2006 or a decline from fair health in 2004 to poor health in 2006.[39]

Walking ability is a powerful predictor of incident disability, institutionalization, and mortality in older persons.[40–42] Participants reported whether they had any difficulty walking across a room, difficulty walking 1 block, or difficulty walking several blocks in 2004 and 2006. We defined incident walking limitation as a report of new onset of difficulty in any of these 3 areas. For each walking measure, less than 2% of respondents reported that they did not do the activity; these participants were coded as having difficulty.

Our objective was to examine associations between these health measures and indicators of material disadvantage in the domains of health care, food, and housing. Health care disadvantage was assessed in 2 ways. First, we identified a group that included both individuals without any form of health insurance (uninsured) and those with a high ratio of out-of-pocket health spending to income (underinsurance). For participants with household incomes of less than 200% of the federal poverty line, underinsurance was defined as out-of-pocket expenditures exceeding 5% of household income; for higher income participants, the underinsurance threshold was 10%.[23] Out-of-pocket expenditures included deductibles, copays, and any health care cost not covered by insurance. For the purposes of this study, the 4% of participants without any current health insurance were combined with the underinsured group. Second, participants were considered to have foregone medications if they reported taking less medication than was prescribed because of cost at any time during the past 2 years.[22]

Food disadvantage was assessed with 2 items.[24,25,43] Participants were considered to have food insufficiency[44] if they answered no to the question, "In the last 2 years, have you always had enough money to buy the food you need?" Participants also reported whether anyone in the household received government food stamps at any time during the past 2 years.

Housing disadvantage was assessed with 4 items. First, participants were classified as owners, renters, or other (e.g., living with family), with renting considered an indicator of material disadvantage on the basis of published reports of poorer health among renters when compared with homeowners.[27,29,45] Participants also reported on housing quality; those who reported fair or poor quality housing were compared with those who reported good quality housing. Housing costing 30% or more of monthly household income was considered unaffordable.[46] Participants who reported fair or poor neighborhood safety were compared with those reporting higher levels of safety.

Demographic covariates were self-reported, including age, gender, marital status (married versus unmarried), years of education, race/ethnicity (non-Hispanic White, non-Hispanic Black, or Hispanic; other race/ethnicity [n=423] was excluded), and income. We calculated poverty status by using self-reported income and household composition.[47] When poor health or other characteristics precluded survey completion, a proxy respondent (usually a spouse or other family member) completed the survey on behalf of the participant; we controlled for 2004 proxy status. In 2004, participants reported whether a doctor had ever told them they had a heart problem (including heart attack, coronary artery disease, angina, congestive heart failure, or other heart condition), cancer (excluding minor skin cancer), stroke, chronic pulmonary disease, or diabetes. Participants were classified as current or former cigarette smokers or as nonsmokers. With the use of self-reported height and weight to calculate body mass index, participants were classified on the basis of National Heart, Lung, and Blood Institute guidelines as underweight, normal weight, overweight, or obese.[48]

Analyses were conducted with Stata version 10 (Stata, College Station, TX) to account for the complex sample design and provide estimates representative of the noninstitutionalized US population. The 2004 HRS response rate was 87.8%. Of the 17 890 age-eligible respondents in 2004, 16 025 also participated in 2006 (89.6%). Between 2004 and 2006, 1000 participants (5.6%) died and 865 were lost to follow-up (4.8%). An additional 190 participants were excluded because of missing data on material resources and 394 were excluded because of missing data on covariates. Baseline information on the 15 441 remaining participants was used to examine cross-sectional associations between demographic characteristics and material disadvantage (Table 1). The χ^2 test was used for descriptive comparisons across groups.

We used logistic regression to predict the odds of decline in self-rated health and incident walking limitations after adjustment for covariates. By definition, a decline could not be observed in participants already in poor health in 2004. Excluding 1153 participants with poor health at baseline, as well as 20 with missing self-rated health data in 2006, yielded a final sample of 14 268 for analyses of decline in self-rated health. For the analysis of incident walking limitations, we similarly excluded 821 participants who already reported difficulty walking across a room in 2004 (the worst category), as well as 11 with missing walking data in 2006, for a final analytic sample of 14 609.

RESULTS

As illustrated in Table 1, we observed differences in the baseline distribution of material disadvantage across age, gender, racial/ethnic, and education groups in all 3 resource domains examined (health care, food, and housing). Differences between older (≥65 years) and younger (51 to 64 years) respondents were significant for all individual components in the health care and food disadvantage domains but were more modest in the housing domain. Participants under 65 years of age, most of whom were not yet eligible for Medicare, reported substantially more problems with foregone prescriptions because of cost (11.5% vs 6.6%). By contrast, uninsurance or underinsurance was more common in the older age group, which reflected a higher prevalence of underinsurance because of both higher health costs and lower incomes. Younger participants fared significantly worse than did adults 65 years and older on indicators of food disadvantage; they reported a higher occurrence of

TABLE 1—Prevalence of Material Disadvantage Among US Adults Aged 51 Years and Older, by Demographic Characteristics: Health and Retirement Study, 2004

		Age			Gender			Race/ethnicity				Years of Education		
	Total, No. or %	51–64 Years, No. or %	≥65 Years, No. or %	*P*	Women, No. or %	Men, No. or %	*P*	Non-Hispanic Black, No. or %	Hispanic, No. or %	Non-Hispanic White, No. or %	*P*	<12 Years, No. or %	≥12 Years, No. or %	*P*
Participants	15 441	6558	8883		8808	6633		2141	1368	11 932		3446	11 995	
Weighted %	100	56.2	43.8		54.0	46.0		9.1	6.6	84.3		17.8	82.3	
Health care														
Foregone prescription	9.4	11.5	6.6	<.001	11.7	6.6	<.001	17.0	15.2	8.1	<.001	13.6	8.5	<.001
Uninsured or underinsured	30.9	25.3	38.0	<.001	35.6	25.2	<.001	36.4	38.3	29.7	<.001	46.2	27.5	<.001
Food														
Insufficiency	2.6	3.5	1.5	<.001	2.9	2.3	.022	7.0	4.8	2.0	<.001	5.5	2.0	<.001
Receipt of food stamps	4.4	4.9	3.8	.030	5.5	3.1	<.001	13.9	14.0	2.6	<.001	13.1	2.5	<.001
Housing														
Renter	12.5	11.8	13.5	.062	13.9	11.0	<.001	29.0	25.3	9.8	<.001	21.8	10.6	<.001
Low-quality housing	10.4	10.8	9.8	.194	10.9	9.7	.008	23.0	25.6	7.8	<.001	23.0	7.6	<.001
Unaffordable housing	14.2	14.5	13.9	.423	15.9	12.2	<.001	23.4	26.7	12.3	<.001	19.6	13.1	<.001
Low neighborhood safety	27.7	26.6	29.2	.034	29.3	25.9	<.001	60.7	53.5	22.2	<.001	47.8	23.4	<.001
Summary indicators														
Health care disadvantage[a]	34.8	30.5	40.3	<.001	40.2	28.4	<.001	42.4	44.2	33.2	<.001	49.9	31.5	<.001
Food disadvantage[b]	6.0	7.0	4.7	<.001	7.1	4.7	<.001	17.6	16.1	3.9	<.001	15.8	3.9	<.001
Housing disadvantage[c]	43.5	42.3	45.1	.031	46.0	40.6	<.001	76.9	72.4	37.6	<.001	65.2	38.8	<.001
Number of domains disadvantaged[d]				<.001			<.001				<.001			<.001
0	41.2	45.5	35.8		36.5	46.8		15.9	18.2	45.8		18.1	46.2	
1	36.1	32.8	40.2		37.1	34.8		39.8	37.6	35.5		40.3	35.1	
2	20.0	18.3	22.0		23.0	16.4		35.8	37.6	16.9		34.3	16.9	
3	2.8	3.4	1.9		3.4	2.1		8.5	6.7	1.9		7.3	1.8	

[a]Self-report of either foregone prescriptions because of cost or uninsurance or underinsurance.
[b]Self-report of either food insufficiency or receipt of food stamps.
[c]Self-report of any of the following: renter, low-quality housing, unaffordable housing, or low neighborhood safety.
[d]Summary of disadvantage in housing, health care, and food domains: 0 = no disadvantage, 3 = disadvantaged in all domains.

both insufficient funds to pay for necessary food and more frequent receipt of food stamps. On every individual indicator studied, women were significantly more likely than were men to be disadvantaged.

The most pronounced differences in material disadvantage occurred across racial/ethnic and educational strata. We observed consistent, substantial, and statistically significant race/ethnicity-based material resource differentials in all 3 domains, as well as for every individual indicator examined. Non-Hispanic Black and Hispanic respondents were far more likely than were non-Hispanic White respondents to report foregoing needed prescriptions because of cost and had a significantly higher prevalence of uninsurance or underinsurance. Similarly pronounced racial/ethnic differentials were observed for health care and food disadvantage. Food insufficiency and food stamp receipt were far more common for non-Hispanic Black and Hispanic respondents than they were for non-Hispanic White respondents. More than 20% of non-Hispanic Black and Hispanic respondents lived in low-quality housing compared with 7.8% of non-Hispanic White respondents. Housing was unaffordable for 23.4% of non-Hispanic Black, 26.7% of Hispanic, and 12.3% of non-Hispanic White respondents. The majority of non-Hispanic Black (60.7%) and Hispanic (53.5%) respondents reported living in unsafe neighborhoods, compared with 22.2% of non-Hispanic White respondents. Across all 3 racial/ethnic groups studied, the majority of participants reported material disadvantage in at least 1 domain. Such disadvantage was particularly common among non-Hispanic Black and Hispanic participants, who often reported multiple unmet needs.

Disparities by educational attainment also were pronounced in our study population. In the domains of health care, food, and housing, and on every individual indicator of disadvantage, respondents with less than a high school education were far more likely than were those with high school diplomas to report material deficits. Examples included the markedly higher occurrence of foregone prescriptions (13.6% vs 8.5%) and uninsurance or underinsurance (46.2% vs 27.5%), as well as large differences in the prevalence of renting rather than owning a home (21.8% vs 10.6%), living in low-quality housing (23.0% vs

TABLE 2—Prevalence of Decline in Self-Rated Health (n = 14 268) and Incident Walking Limitation (n = 14 609) Among US Adults Aged 51 Years and Older With Specified Types of Material Disadvantage: Health and Retirement Study, 2004 and 2006

	Decline in Self-Rated Health			Incident Walking Limitation		
	Yes, No. or %	No, No. or %	*P*	Yes, No. or %	No, No. or %	*P*
Respondents	1936			2547		
Weighted %	12.3			15.8		
Health care						
Foregone prescription	19.7	11.6	<.001	26.4	14.8	<.001
Uninsured or underinsured	17.9	9.9	<.001	22.9	12.9	<.001
Food						
Insufficiency	25.8	12.0	<.001	31.0	15.5	<.001
Receipt of food stamps	27.7	11.7	<.001	30.5	15.2	<.001
Housing						
Renter	17.5	11.3[a]	<.001	21.1	14.8[a]	<.001
Low-quality housing	19.1	11.6	<.001	23.8	15.0	<.001
Unaffordable housing	15.4	11.8	<.001	17.9	15.5	.002
Low neighborhood safety	17.4	10.4	<.001	20.8	14.0	<.001
Summary indicators						
Health care disadvantage[b]	17.8	9.5	<.001	22.6	12.4	<.001
Food disadvantage[c]	26.6	11.6	<.001	30.9	15.0	<.001
Housing disadvantage[d]	16.2	9.5	<.001	19.1	13.4	<.001
Number of domains disadvantaged[e]			<.001			<.001
0	7.3			10.6		
1	13.7			17.0		
2	19.2			23.2		
3	29.1			33.1		

Note. Among adults with and without the material disadvantage specified, the table reports the proportion that experienced the adverse outcomes.
[a]Proportion of homeowners reporting outcome of interest.
[b]Self-report of either foregone prescriptions because of cost or uninsurance or underinsurance.
[c]Self-report of either food insufficiency or receipt of food stamps.
[d]Self-report of any of the following: renter, low-quality housing, unaffordable housing, or low neighborhood safety.
[e]Summary of disadvantage in housing, health care, and food domains: 0 = no disadvantage, 3 = disadvantaged in all domains.

7.6%), and living in an unsafe neighborhood (47.8% vs 23.4%). Food insufficiency (5.5% vs 2.0%) and food stamp receipt (13.1% vs 2.5%) were also substantially more common in respondents without a high school diploma.

As illustrated in Table 2, disadvantaged individuals were markedly more likely than were their advantaged counterparts to experience declines in self-rated health and incident walking limitations. More than 1 in 10 participants reported a decline in self-rated health (12.3%) or incident walking limitations (15.8%) between 2004 and 2006. For all individual and summary measures of health care, food, and housing disadvantage, we observed higher rates of worsening health among participants without adequate material resources.

The results of logistic regression models designed to determine the independent health effects of each demographic indicator and domain of disadvantage are reported in Table 3. The analysis of declines in self-rated health (Table 3) excluded participants who already reported poor health in 2004. In model 1, which predicted a decline in self-rated health with the use of only demographic characteristics, declines were more common among older, Black or Hispanic (compared with White), and unmarried respondents, as well as those with less than a high school education and those living in poverty.

Next, in model 2, we assessed the association between dichotomous indicators of health care, food, and housing disadvantage and decline in self-rated health. Disadvantage in each domain was associated with significantly elevated odds of decline in self-rated health, with the strongest associations observed for food disadvantage (odds ratio [OR]=2.10; 95% confidence interval [CI]=1.65, 2.68). These results were largely unchanged after we controlled for demographic characteristics (model 3). The relations between being non-Hispanic Black and being unmarried and health declines were rendered nonsignificant after we controlled for material disadvantage, and the estimated effects of poverty, Hispanic ethnicity, and education were attenuated. Even after we further controlled for baseline self-rated health, comorbid conditions, weight status, and smoking status (model 4), health care, food, and housing disadvantage were independently associated with the odds of a decline in self-rated health. The effect was strongest for food disadvantage (OR=1.69; 95% CI=1.29, 2.22), followed by health care (OR=1.39; 95% CI=1.23, 1.58) and housing (OR=1.20; 95% CI=1.07, 1.35) disadvantage. Effect estimates for each type of disadvantage were comparable with those observed for a range of comorbid conditions, including diabetes and stroke.

Comparable results for incident walking limitations are also shown in Table 3, again showing the strongest effect for food disadvantage (OR=1.64; 95% CI=1.31, 2.05), followed by health care disadvantage (OR=1.43; 95% CI=1.29, 1.58). Housing disadvantage was not a significant predictor of walking limitations after we controlled for baseline walking limitations, comorbid conditions, weight status, and cigarette smoking status (model 4).

We used similar models that controlled for all covariates to examine the independent contributions to both outcomes of the component indicators that constitute health care, food, and housing disadvantage (results not shown). Both indicators of health care disadvantage (foregone prescriptions because of cost and uninsurance or underinsurance) were significantly associated with self-rated health declines and incident walking limitations. We observed significantly elevated odds of decline in self-rated health among food stamp recipients (OR=1.48; 95% CI=1.10, 2.00), as well as elevations

TABLE 3—Relative Odds of Decline in Self-Rated Health and Incident Walking Limitation Among US Adults Aged 51 Years and Older: Health and Retirement Study, 2004 and 2006

	Model 1: Demographic-Only Model, OR (95% CI)	Model 2: Disadvantage-Only Model, OR (95% CI)	Model 3: Adjusted Model, OR (95% CI)	Model 4: Full Model, OR (95% CI)
Decline in self-rated health (n = 14 268)				
Demographics				
Age, y	1.03 (1.02, 1.03)		1.03 (1.02, 1.03)	1.02 (1.02, 1.03)
Female	0.93 (0.83, 1.05)		0.90 (0.79, 1.02)	0.98 (0.84. 1.14)
Non-Hispanic Black	1.26 (1.06, 1.49)		1.12 (0.96, 1.31)	1.12 (0.95, 1.31)
Hispanic	1.58 (1.32, 1.89)		1.44 (1.21, 1.73)	1.70 (1.42, 2.04)
Less than high school education	1.71 (1.51, 1.94)		1.55 (1.37, 1.76)	1.47 (1.29, 1.69)
Poverty	1.52 (1.30, 1.78)		1.16 (1.00, 1.35)	1.18 (1.01, 1.37)
Unmarried	1.23 (1.07, 1.41)		1.06 (0.93, 1.22)	1.06 (0.91, 1.23)
Disadvantage				
Any health care disadvantage[a]		1.82 (1.62, 2.05)	1.62 (1.44, 1.82)	1.39 (1.23, 1.58)
Any food disadvantage[b]		2.10 (1.65, 2.68)	1.88 (1.46, 2.43)	1.69 (1.29, 2.22)
Any housing disadvantage[c]		1.53 (1.37, 1.70)	1.35 (1.21, 1.51)	1.20 (1.07, 1.35)
Comorbid conditions				
Heart disease				1.49 (1.28, 1.73)
Cancer				1.33 (1.10, 1.60)
Stroke				1.62 (1.26, 2.09)
Pulmonary disease				1.77 (1.47, 2.12)
Diabetes				1.36 (1.14, 1.61)
Smoking status				
Never smoker (Ref)				1.00
Former smoker				1.14 (1.00, 1.30)
Current smoker				1.52 (1.28, 1.80)
Weight status				
Underweight				1.82 (1.21, 2.76)
Normal weight (Ref)				1.00
Overweight				1.04 (0.87, 1.25)
Obese				1.26 (1.07, 1.49)
Baseline self-rated health				
Excellent (Ref)				1.00
Very good				2.24 (1.55, 3.23)
Good				6.27 (4.52, 8.71)
Fair				2.42 (1.66, 3.53)
Incident walking limitation (n = 14 609)				
Demographics				
Age, y	1.04 (1.03, 1.05)		1.04 (1.03, 1.05)	1.05 (1.04, 1.05)
Female	1.24 (1.10, 1.38)		1.20 (1.07, 1.34)	1.30 (1.16, 1.45)
Non-Hispanic Black	1.14 (0.96, 1.36)		1.06 (0.90, 1.24)	1.04 (0.88, 1.23)
Hispanic	0.96 (0.79, 1.17)		0.91 (0.75, 1.11)	1.03 (0.84, 1.27)
Less than high school education	1.63 (1.47, 1.81)		1.49 (1.34, 1.66)	1.35 (1.22, 1.51)
Poverty	1.54 (1.33, 1.78)		1.19 (1.03, 1.37)	1.16 (0.99, 1.37)
Unmarried	1.18 (1.05, 1.32)		1.05 (0.93, 1.18)	1.05 (0.93, 1.19)

Continued

TABLE 3—*Continued*

Disadvantage			
Any health care disadvantage[a]	1.90 (1.74, 2.08)	1.59 (1.44, 1.76)	1.43 (1.29, 1.58)
Any food disadvantage[b]	2.04 (1.67, 2.48)	2.00 (1.62, 2.48)	1.64 (1.31, 2.05)
Any housing disadvantage[c]	1.25 (1.12, 1.40)	1.13 (1.01, 1.28)	1.06 (0.94, 1.19)
Comorbid conditions			
Heart disease			1.34 (1.17, 1.54)
Cancer			1.03 (0.89, 1.20)
Stroke			1.72 (1.38, 2.15)
Pulmonary disease			1.66 (1.38, 2.00)
Diabetes			1.31 (1.11, 1.55)
Smoking status			
Never smoker (Ref)			1.00
Former smoker			1.08 (0.95, 1.22)
Current smoker			1.65 (1.36, 2.01)
Weight status			
Underweight			1.42 (1.01, 2.00)
Normal weight (Ref)			1.00
Overweight			1.16 (1.01, 1.34)
Obese			1.94 (1.67, 2.26)
Baseline walking ability			
No difficulty (Ref)			1.00
Difficulty walking several blocks			1.43 (1.20, 1.71)
Difficulty walking 1 block			0.68 (0.55, 0.85)

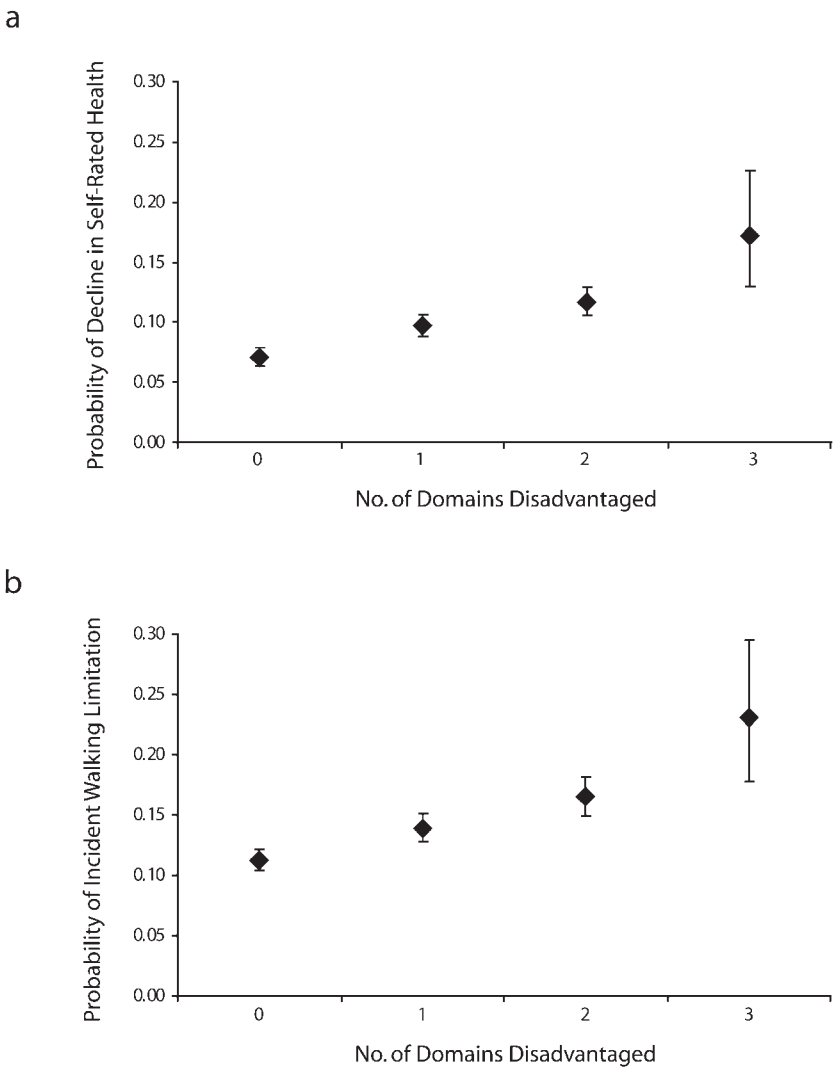
Note. OR = odds ratio; CI = confidence interval.
[a]Self-report of either foregone prescriptions because of cost or uninsurance or underinsurance.
[b]Self-report of either food insufficiency or receipt of food stamps.
[c]Self-report of any of the following: renter, low-quality housing, unaffordable housing, or low neighborhood safety.

approaching statistical significance among participants reporting insufficient money for food (OR=1.47; 95% CI=0.92, 2.36; *P*=.104). For incident walking limitations, we observed elevated point estimates for both insufficient money for food (OR=1.47; 95% CI=0.95, 2.26; *P*=.082) and food stamp receipt (OR=1.26; 95% CI=0.96, 1.65; *P*=.095), although neither was statistically significant. In the housing domain, only living in an unsafe neighborhood was significantly associated with decline in self-rated health (OR=1.17; 95% CI=1.02, 1.34), whereas both unsafe neighborhood conditions (OR=1.17; 95% CI=1.05, 1.30) and poor housing quality (OR=1.20; 95% CI=1.03, 1.41) were associated with higher odds of incident walking limitations.

The predicted probability of declines in self-rated health and incident walking limitations are provided in Figure 1. The probabilities shown are based on the number of domains disadvantaged, with control for all covariates in model 4. We observed a monotonic pattern of more frequent declines in self-rated health and walking limitations among respondents with a higher number of domains disadvantaged, such that the highest risk was observed in respondents disadvantaged in all 3 domains.

DISCUSSION

Our findings provided evidence that health is shaped by unmet needs for adequate food, housing, and health care. We observed that most Americans over 50 years of age experienced at least 1 material disadvantage in these domains. The most common problems were low neighborhood safety (27.7%) and uninsurance or underinsurance (30.9%). Consistent with previous reports on racial/ethnic and socioeconomic disparities, non-Hispanic Black and Hispanic respondents and those without a high school education were markedly more likely to report disadvantage for every indicator studied.[49] For example, nearly 9% of non-Hispanic Blacks (vs 2% of non-Hispanic Whites) experienced disadvantage in all 3 domains studied, as did 7% of participants with less than a high school education (and 2% of those with high school education). These differences are both a telling reminder of the distribution of disadvantage in the United States and a likely explanation for profound and enduring health disparities. Strong relations between health declines and non-Hispanic Black race, low education, poverty, and unmarried status were attenuated or eliminated after we controlled for indicators of material disadvantage. Although not the primary focus of this article, these findings suggest that differential access to necessary material resources may be 1 pathway through which non-Hispanic Blacks and other



Note. Predicted probability using regression model 4, setting the value of each covariate to equal the sample mean value: demographics (age, gender, race/ethnicity, education, poverty, marital status, and proxy report), comorbid conditions (heart disease, cancer, stroke, pulmonary disease, and diabetes), weight status, smoking status, and (a) baseline self-rated health or (b) baseline walking limitations; error bars represent 95% confidence intervals.

FIGURE 1—Number of domains disadvantaged and adjusted probability of decline in (a) self-rated health and (b) incident walking limitation: Health and Retirement Study, United States, 2004 and 2006.

disadvantaged populations experience poorer health outcomes.

The effects we observed were substantial and sustained even after we controlled for a range of covariates, including baseline health status and comorbidities. In general, the estimated health effects of material disadvantage were similar to associations observed between comorbid illness and declines in health. For example, our results suggest that food disadvantage is as strong a predictor of later health declines as is heart disease, cancer, stroke, pulmonary disease, or diabetes.

These results reaffirm a large body of research demonstrating the toll of inadequate health care access and underinsurance on the health of Americans.[21–23,39,50] Our findings also emphasize the interconnectedness of material resources and the need for multifaceted policies to improve population health.[12,51] Policy interventions to address 1 material domain may have spillover effects on other domains, as illustrated by the introduction of Medicare Part D prescription drug coverage in 2006, after the start of this study. Medicare Part D may have reduced financial constraints for older adults in a way that both improves access to needed medications and frees money to purchase other necessities, like food.[52] Similar arguments could be made about how policy initiatives to address neighborhood safety and housing quality are likely to impact population health.

Both researchers and policymakers have recognized the need to coordinate efforts to ensure access to adequate material resources across domains.[3,53–55] For example, the Department of Housing and Urban Development has combined the delivery of housing services with onsite health care for low-income older persons and persons with disabilities.[55] Material disadvantage may be reduced substantially with appropriate planning for retirement, but this will also require improving the current levels of financial literacy among older persons in the United States.[33] Efforts to improve the health of the nation may be more effective if they simultaneously address a range of basic needs instead of individual social or economic domains alone.

Material disadvantage, and policies to remediate that disadvantage, may influence health through several pathways, including direct physical effects, behavioral influences, and stress or mental health effects. For example, food disadvantage may operate through each of these pathways. Food disadvantage was strongly associated with health declines, which supports the contention that current food stamp benefit levels of approximately $1 per meal may be inadequate to maintain health.[26] Nutritional compromise may lead to frailty and associated functional impairments.[24,44,56] Insufficient money for food may lead individuals to choose inexpensive, unhealthy foods, leading to the paradox of overweight among adults with food insufficiency.[57] Being unable to provide needed food for oneself or one's family represents a stressor, and both acute and chronic stress have been linked to a variety of adverse physiologic responses.[58,59] Finally, food disadvantage, the least common form of disadvantage in this study, may simply serve as a sensitive indicator of

extreme disadvantage. Similarly, housing disadvantage may affect health through multiple pathways,[60,61] with poor housing quality presenting environmental hazards (e.g., poor indoor air quality), and unsafe neighborhood conditions leading to reduced physical activity and increased stress.[62]

Several limitations should be taken into account in interpreting the results of this study. First, we relied on self-reported material disadvantage and health outcomes. Differential reporting of material disadvantage may bias estimated differences across demographic groups. Additionally, the validity of self-rated health as a predictor of mortality may vary across socioeconomic groups, although evidence is mixed.[63–65] Second, we used longitudinal data to predict change in health accounting for baseline characteristics, but this analysis cannot prove conclusively that material disadvantage causes poor health. Other factors, including health earlier in life,[66,67] self-efficacy,[68] and institutional barriers (e.g., racism)[69] may affect both health and late-life access to material resources. Furthermore, some indicators are related to both need for and use of services. For instance, only participants who needed prescriptions were at risk of forgoing prescriptions because of cost. Similarly, underinsurance was based on the ratio of health expenses to income; this measure may reflect a high need for health services (poor health) and inadequate health benefit arrangements. Third, the large number of comparisons conducted may increase the probability of type 1 error. Finally, our sample excluded 2449 individuals with missing data, including 1000 who died and 865 who were lost to follow-up between 2004 and 2006. Participants with missing data had a higher number of domains disadvantaged and had worse self-rated health and a higher prevalence of walking limitations at baseline. They were also older and more likely to be non-Hispanic Black or Hispanic, to have less than a high school education, to be in poverty, and to be unmarried; in addition, they also had a greater prevalence of chronic conditions. Thus, we are likely have underestimated the prevalence of material disadvantage in 2004.

Despite these limitations, this study demonstrated the importance of considering health care, food, and housing as determinants of population health and health disparities. Each of these factors contributed to declines in self-rated health and incident walking limitations—2 important indicators of future morbidity and mortality risk—in this nationally representative sample of adults over 50 years of age. Older adults with multiple forms of material disadvantage were at particularly increased risk of health decline and functional impairment. Strategies to improve population health and to reduce health disparities must address a range of basic human needs, including affordable, quality health care, food, and housing. ■

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This article was accepted May 31, 2009.

Contributors

D.E. Alley and C. Cannuscio were responsible for study design, interpretation of results, and drafting of the article. B.J. Soldo, J.A. Pagan, and D.A. Asch assisted in the interpretation of results and critical revisions of the article. J. McCabe and S.H. Field assisted with data coding and analysis. M. deBlois assisted with drafting of the article.

Acknowledgments

This study was supported by the Robert Wood Johnson Foundation Health & Society Scholars program. B.J. Soldo and J. McCabe were supported by National Institute on Aging (grant R01 AG023370 and P30 AG012836). J.A. Pagán acknowledges the support of the Department of Defense (grant W81XWH-06-1-0334), the Agency for Healthcare Research and Quality (grant R24HS017003), and the Centers for Disease Control and Prevention (grant 1H75DP001812-01).

The authors thank Sarah Sanchez for her research assistance.

Note. The contents are solely the responsibility of the authors and do not reflect the views of the study sponsors. The authors had no conflicts of interest to report.

Human Participant Protection

Institutional review board approval was granted by the University of Pennsylvania.

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VOLUME 26 · NUMBER 11 · APRIL 10 2008

JOURNAL OF CLINICAL ONCOLOGY

ORIGINAL REPORT

Lack of Community Insurance and Mammography Screening Rates Among Insured and Uninsured Women

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Submitted September 26, 2007; accepted January 10, 2008.

Supported by the Department of Defense Breast Cancer Research Program under award number W81XWH-06-1-0334.

Authors' disclosures of potential conflicts of interest and author contributions are found at the end of this article.

Views and opinions of, and endorsements by, the authors do not reflect those of the US Army or the Department of Defense.

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0732-183X/08/2611-1865/$20.00

DOI: 10.1200/JCO.2007.14.5664

ABSTRACT

Purpose
To evaluate whether the proportion of the local population without health insurance coverage is related to whether women undergo mammography screening.

Methods
Survey data on 12,595 women 40 to 69 years of age from the 2000 to 2001 Community Tracking Study Household Survey were used to analyze the relation between community lack of insurance and whether the respondent had a mammogram within the past year.

Results
Women age 40 to 69 were less likely to report that they had a mammogram within the last year if they resided in communities with a relatively high uninsurance rate, even after adjusting for other factors. After adjusting for individual insurance and other factors, a 10-percentage-point decrease in the proportion of the local insured population is associated with a 17% (95% CI, 13% to 21%) decrease in the odds that a woman age 40 to 69 years will undergo mammography screening within a year.

Conclusion
Women living in communities with high uninsurance are substantially less likely to undergo mammography screening. These results are consistent with the view that the negative impact of uninsurance extends to everyone in the community regardless of individual health insurance status.

J Clin Oncol 26:1865-1870. © 2008 by American Society of Clinical Oncology

INTRODUCTION

About 47 million people in the United States do not have health insurance coverage, and the number of uninsured will keep rising if health insurance premiums continue to grow faster than earnings.[1-3] Lack of insurance clearly has a direct affect on the health of the uninsured population. The general health status of uninsured adults tends to decrease faster than that of insured adults, and uninsured adults have a higher risk of dying prematurely than do insured adults.[4] Many studies have shown that uninsured adults are more likely to lack access to health care and receive lower-quality health care—including preventive care—than are insured adults.[4,5] Lack of health insurance coverage has also been linked to delays in the detection of breast cancer and a threefold decrease in the probability of undergoing routine mammography screening.[6,7,8]

Lack of insurance may also be associated with reduced care for the surrounding insured population if high levels of community uninsurance create financial stress on local health care systems. There is substantial variation in the relative size of the uninsured population across communities and states in the United States.[9,10] For example, uninsurance rates can range from 5% to 10% in communities in Pennsylvania and New York to 25% to 35% in communities in California and Texas. Health care providers located in communities with a large uninsured population may have few sources of revenue, inducing them to reduce the mix, quantity, and quality of health services provided. Public safety-net providers may also be forced to limit health care services because regional governments may be unable to provide health care for a large uninsured population.[11]

Mammography services may be particularly sensitive to community insurance rates for several reasons. Reimbursement for mammography services has declined substantially during the last 10 years and, as such, providing screening mammography can be a financial liability for a health system or free-standing radiology facility.[12] Furthermore, mammography's capital-intensive cost structure makes mammography facilities financially sensitive

to changes in the demand for their services. The US Food and Drug Administration (FDA) has estimated that average costs decrease until "about the 80th percentile of the [mammography] volume distribution observed among U.S. [screening] facilities, so that most facilities operate at inefficient scale."[13] That is, mammography screening facilities must operate near full capacity to cover their fixed costs. If uninsured individuals are more likely to forego preventive services, high levels of community uninsurance may decrease the volume of services delivered by mammography facilities and effectively increase the average costs of providing screening services.[4,13]

Mammography use may also be particularly sensitive to community uninsurance because of the growing shortage of breast radiologists and certified mammography technologists. If radiologists and technologists are in high demand, they may be unlikely to locate in communities where the profit from and the demand for screening mammography is relatively low. Supporting this hypothesis, a 2001 to 2002 survey indicated that the radiologist shortage was greater in nonprofit facilities and that facilities reporting lower rates of mammograms also appear to have the most difficulty retaining certified technologists.[14] Recent evidence also suggests that the number of mammography facilities in the United States is declining. The FDA reported 8,832 certified facilities with 13,399 accredited units as of September 1, 2007, a decline of 480 mammography facilities compared with October 2002.[15] This consolidation may further limit access to mammography screening and is likely to continue as existing mammography units are updated to digital imaging machines, which provide higher-quality images and computer-assisted diagnosis but at a higher cost.[16]

The purpose of this study is to examine whether low rates of community insurance are associated with reduced use of mammography screening for both insured and uninsured adult women. Survey data from the 2000 to 2001 Community Tracking Study Household Survey (CTSHS) is used to estimate multilevel logistic regression models of the determinants of mammography screening. Multilevel statistical modeling accounts the contextual effects of local-level lack of insurance and allows for the inclusion of community-specific random effects.[17] The main hypothesis of the study is that both insured and uninsured women residing in communities with a relatively large uninsured population are less likely to undergo mammography screening than if they resided in communities with a relatively small uninsured population.

METHODS

Data Source

The 2000 to 2001 CTSHS (N = 59,725) was developed to track changes in local health care systems, and the sample collected is representative of households in the 48 contiguous states.[18] The CTSHS includes information on household composition, demographic and socioeconomic characteristics, health status, health care utilization and personal experiences with the US health care system. Interviews were conducted from September 2000 to September 2001.

Fifty-one metropolitan areas and nine nonmetropolitan areas in the contiguous US were selected at random, and respondent households were drawn from these communities using random-digit dialing. This telephone sample was augmented with a sample of households that did not have a phone. Larger samples were drawn from 12 communities selected for more in-depth analyses. These communities were Boston, MA; Cleveland, OH, Greenville, SC; Indianapolis, IN; Lansing, MI; Little Rock, AK; Miami, FL; Newark, NJ; Orange County, CA; Phoenix, AZ; Seattle, WA; and Syracuse, NY. The selected sites are defined as local health care markets in the sense that this is where residents within the boundaries of these communities receive their health care, whereas providers mostly serve residents living in these communities. Most of the sites are metropolitan statistical areas defined by the US Office of Management and Budget and nonmetropolitan economic areas defined by the US Bureau of Economic Analysis.[18]

Individuals in households selected for interviews were classified into family insurance units (ie, family groupings consisting of an adult household member, his/her spouse and dependent children under the age of 18, or any dependent children who were full-time students between the ages of 18 and 22 years).[18] We used only the core CTSHS data (60 sites) because we were interested in estimating the proportion of the adult population without health insurance coverage residing in each site (ie, the uninsured population 18 years of age and older). After estimating community-level uninsurance rates, we further restricted the sample to women 40 to 69 years of age (n = 13,438). We also excluded a supplemental sample of 773 residents living outside the 60 CTSHS sites as well as 70 respondents with missing data in our variables of interest. Our final sample consisted of 12,595 women.

Variables

We analyzed how the proportion of the local population without health insurance coverage was related to mammography screening among both insured and uninsured women. We calculated the proportion of the local uninsured population in each of the 60 CTSHS sites using person-level sampling weights specifically developed for community-level estimates.[18] We determined individual insurance status by responses to the following question: "According to the information we have, [NAME] does not have health care coverage of any kind. Does [NAME] have health insurance or coverage through a plan I might have missed?" Those answering no to this question are classified as uninsured. All persons covered by private insurance, Medicare, Medicaid, military, state, or other plans are classified as insured. Extant research has shown that self-reported telephone survey data of health insurance status are accurate and valid.[19,20]

Our dependent variable was defined as whether the respondent reported she had a mammogram within the past year, constructed from answers to the following two questions: "A mammogram is an x-ray of the breast to look for breast cancer. Has [NAME] ever had a mammogram?" The question was asked to all women age 40 or older. If the answer was yes then there was a follow-up question: "How long has it been since [NAME] had (her/your) last mammogram?" Previous studies have shown that self-report is a valid method of collecting mammography data.[21-23]

Our specification of the multilevel logistic regression model for mammography screening was based on the idea that the use of preventive health care is determined by the need for preventive health care services, individual predisposing characteristics, enabling factors at the individual level, and community contextual factors.[24,25] Need variables included self-reported health status (fair, poor, good, very good, and excellent) and whether the respondent had zero, one, or two or more chronic health conditions (diabetes arthritis, asthma, chronic obstructive pulmonary disease, hypertension, coronary heart disease, cancer, or depression). Individual predisposing characteristics included three age categories (40 to 49, 50 to 59, and 60 to 69 years of age), four education categories ($\leq$ 11, 12, 13-15, and $\geq$16 years), racial/ethnic background (white, African American, Hispanic, or other), and whether the respondent was married. Enabling factors at the individual level included health insurance coverage and four family poverty level categories (0% to 99%, 100% to 199%, 200% to 299%, and $\geq$ 300%).

We included community-level variables to capture the ability of localities to support health-related services. In addition to our main independent variable of interest, the proportion of the local population without health insurance coverage, we adjusted for community-level median household income, a summary measure of community wealth, and the Gini coefficient, a summary measure of community income inequality. The Gini coefficient ranges from 0 (perfectly equal distribution of income) to 1 (all income in the community goes to one person or household).[26] Community wealth and income inequality have been shown to be related to health care utilization and health outcomes (eg, mortality).[27] Median household income is positively correlated

with the demand for medical care and the level of health. Income inequality could be related to health because it may reflect the degree of social distance across different income groups as well as disparities in community-level spending in health care.[28] Income inequality could also reduce social cohesion, which could affect the likelihood that individuals will support more spending in local public health programs, which may include breast cancer prevention.[29] All of the contextual level variables were estimated using person-level sampling weights designed for site-specific estimates.[18]

Statistical Approach

We used multilevel logistic regression to analyze how mammography screening among both insured and uninsured women was related to community uninsurance. Multilevel logistic regression is ideal for this study because we are interested in an individual-level dichotomous dependent variable and we have both community- and individual-level variables as predictors.[30] The hierarchical model included random effects to account for dependence in the variation in community effects within each of the 60 communities, and it was estimated using the GLLAMM (Generalized Latent, Linear, and Mixed Models) program in Stata 9.2 (StataCorp LP, College Station, TX).[31]

RESULTS

Mammography Screening and Lack of Insurance

Table 1 presents the characteristics of the full sample as well as the characteristics of separate samples of women who had and did not have a mammogram within the last year. Ten percent of women in this age group were uninsured, and 57% of women had a mammogram within the last year. However, screening rates were substantially different across health insurance status. Approximately 60% of insured women had a mammogram within the last year compared with 26% of uninsured women (not shown).

In addition, large and statistically significant sociodemographic differences distinguished women who had a mammogram from those who did not. Women undergoing mammography screening were relatively older, more educated, more likely to be insured, less likely to come from ethnic/racial minority populations, more likely to be married, and had higher income and better self-reported health.

Table 1. Sample Rates and Means for Women Age 40 to 69 Years, by Mammography Screening

Variable	All	Mammography Screening: Yes (57.17%)	Mammography Screening: No (42.83%)	P*
Individual-level variables				
Uninsured, %	10.12	4.66	17.41	.00
Age group, %				
40-49 years	43.77	37.39	52.28	.00
50-59 years	32.70	35.50	28.96	.00
60-69 years	23.53	27.11	18.75	.00
Race/ethnicity (%)				
White	75.17	77.11	72.57	.00
African American	11.44	10.97	12.05	.13
Hispanic	9.56	8.57	10.89	.00
Other	3.84	3.35	4.48	.03
Years of education, %				
≤ 11	13.39	11.21	16.30	.00
12	35.31	35.17	35.50	.76
13-15	28.06	27.98	28.16	.86
≥ 16	23.24	25.63	20.05	.00
Married, %	62.65	66.47	57.56	.00
Family poverty level, %				
0-99	10.52	8.19	13.63	.00
100-199	14.07	11.60	17.35	.00
200-299	16.43	15.59	17.55	.05
≥ 300	58.98	64.61	51.47	.00
Self-reported health status, %				
Fair	14.24	13.30	15.50	.02
Poor	5.50	4.88	6.34	.01
Good	28.28	27.56	29.25	.14
Very good	35.70	36.86	31.83	.00
Excellent	17.27	17.41	17.08	.70
Chronic health conditions, %				
No chronic conditions	36.46	32.97	41.12	.00
One chronic condition	25.41	26.88	23.45	.00
Two or more chronic conditions	38.13	40.15	35.43	.00
Community-level variables				
Community uninsurance, %	12.51	12.31	12.78	.00
Median household income/$1,000	40.47	40.70	40.16	.07
Gini coefficient	0.41	0.41	0.41	.67

*Wald test of differences in rates and means by mammography screening.

Multilevel Logistic Regression Model of Mammography Screening

Table 2 reports the results from a multilevel logistic model of mammography screening for women age 40 to 69 years. Model 1 reports the results including individual health insurance status and the percentage uninsured in the community (divided by 10). Uninsured women were substantially less likely to have undergone mammography than insured women (odds ratio [OR] = 0.23; 95% CI, 0.19 to 0.28). High community uninsurance rate was also associated with a lower mammography screening propensity (OR = 0.87; 95% CI, 0.83 to 0.90).

Model 2 includes individual demographic and socioeconomic characteristics (years of age, race/ethnicity and years of education, marital status, family poverty level, self-reported health status, and number of chronic health conditions). Model 3 adds community-level characteristics (median household income divided by $1,000 and the Gini coefficient, an index of community income inequality) to the multilevel logistic regression model. Even after adjusting for individual health insurance coverage as well as other individual and community-level characteristics, a 10-percentage-point increase in the proportion of the local population without health insurance coverage is associated with a 17% decrease in the odds that a woman age 40 to 69 years will undergo mammography screening within a year (OR = 0.83; 95% CI, 0.79 to 0.87).

The three multilevel models were also estimated with an interaction term between individual health insurance status and community uninsurance, but the coefficient was statistically insignificant in all three specifications. Thus, the community uninsurance effect on mammography screening did not vary by health insurance status. Another important issue is that mammography screening is not universally endorsed for women age 40 to 49. To address this concern, the statistical analyses were repeated excluding this age group but the main results did not change.

Figure 1 graphs the relation between the community-level weighted-mean predicted probability of undergoing mammography screening and the proportion of the population without health insurance coverage in each of the 60 CTSHS communities. These probabilities are adjusted using the estimated multilevel logistic regression

Table 2. Adjusted Odds Ratios of Undergoing Mammography Screening Within the Last Year, Women Age 40 to 69 Years

Characteristic	Model 1		Model 2		Model 3	
	Odds Ratio	95% CI	Odds Ratio	95% CI	Odds Ratio	95% CI
Uninsured	0.23†	0.19 to 0.28	0.31†	0.25 to 0.37	0.31†	0.25 to 0.37
% uninsured in community/10	0.87†	0.83 to 0.90	0.86†	0.83 to 0.90	0.83†	0.79 to 0.87
Age, years						
40-49			Ref		Ref	
50-59			1.70†	1.57 to 1.84	1.70†	1.57 to 1.84
60-69			1.96†	1.72 to 2.25	1.97†	1.72 to 2.26
Race/ethnicity						
White			Ref		Ref	
African American			1.16*	1.03 to 1.32	1.14*	1.00 to 1.31
Hispanic			1.23*	1.04 to 1.46	1.26*	1.05 to 1.51
Other			0.88	0.68 to 1.14	0.89	0.68 to 1.15
Years of education						
≤ 11			Ref		Ref	
12			1.23†	1.05 to 1.43	1.23*	1.04 to 1.47
13-15			1.22†	1.05 to 1.41	1.22*	1.05 to 1.43
≥ 16			1.45†	1.23 to 1.71	1.46†	1.23 to 1.74
Married			1.33†	1.20 to 1.47	1.32†	1.19 to 1.46
Family poverty level, %						
0-99			Ref		Ref	
100-199			0.99	0.83 to 1.19	0.99	0.83 to 1.19
200-299			1.14	0.99 to 1.32	1.14	0.98 to 1.33
≥ 300			1.37†	1.16 to 1.61	1.38†	1.15 to 1.64
Self-reported health status						
Fair			0.90	0.75 to 1.09	0.90	0.75 to 1.09
Poor			0.78*	0.62 to 0.98	0.78*	0.63 to 0.97
Good			0.90	0.77 to 1.05	0.90	0.77 to 1.04
Very good			1.09	0.97 to 1.23	1.09	0.97 to 1.23
Excellent			Ref		Ref	
No. of chronic health conditions						
0			Ref		Ref	
1 chronic condition			1.34†	1.19 to 1.50	1.33†	1.19 to 1.50
≥ 2			1.38†	1.21 to 1.59	1.38†	1.20 to 1.59
Median household income/$1,000					1.01†	1.01 to 1.02
Gini coefficient					1.05†	1.04 to 1.06

Abbreviation: Ref, reference value.
*Statistically significant at the .05 level.
†Statistically significant at the .01 level.

parameters, and they take into account the estimated random effects. The fitted line clearly shows that the mammography screening probability is negatively related to community uninsurance. The slope of the fitted line suggests that, if community uninsurance increases by 10 percentage points, then the community-level weighted-mean probability of mammography screening would fall by 0.064 points.

The community uninsurance elasticity for mammography screening can be estimated at the sample means by multiplying the slope of the fitted line by the mean community uninsurance rate divided by the mean predicted probability of mammography screening. This unit-free elasticity measure is equal to –.13, which suggests that the probability of mammography screening falls by 1.3% for every 10% increase in community uninsurance.

DISCUSSION

A growing body of literature demonstrates the association between individual-level uninsurance and worse health care and health outcomes. This study shows that lack of insurance within a community is associated with reduced mammography use among women in this community, regardless of whether these women are themselves insured. These effects are large and important. The effects are large, because every one-percentage-point decrease in community insurance rates is associated with a 2% decrease in the likelihood of individual mammography use among insured or uninsured women. The results are important because they demonstrate that uninsurance is not just a problem for the uninsured, but it is a dilemma for everyone in society regardless of individual health insurance status.

Most studies about the negative consequences of uninsurance focus on its association with lower access to health care and poorer health. These studies do not consider how local health care systems are stressed by lack of community insurance or, more generally, how uninsurance is a social ill that affects broad and seemingly protected populations.[32,33]

This study is subject to several limitations. The definition of a community in the CTSHS is a relatively large collection of counties or

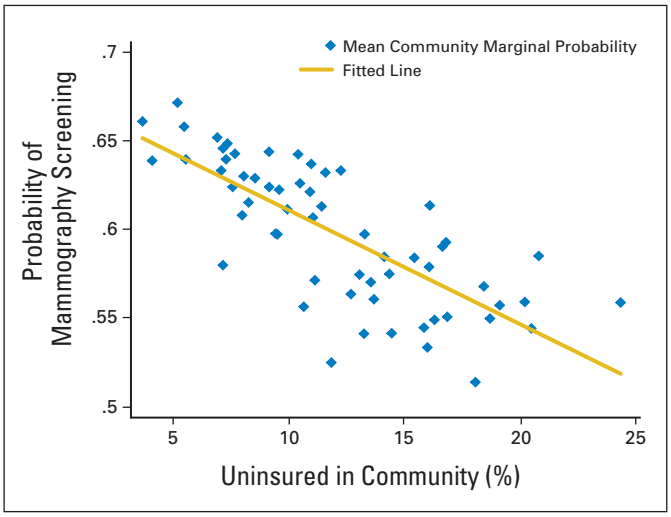

Fig 1. Probability of undergoing mammography screening by percentage of uninsured in a community.

a metropolitan area, and it is unclear what would be the appropriate community size when one studies a preventive health care service such as mammography screening. However, larger sampled community sizes would likely understate the true effects of community uninsurance. Second, our data rely substantially on self-report, and some informants may incorrectly report insurance status or receipt of mammography. Third, the Centers for Disease Control and Prevention provide funding for mammography screening services to low-income women who are uninsured or underinsured through the National Breast and Cervical Cancer Early Detection Program. The availability of these types of programs may affect the results of this study given that this information is not available in the CTSHS.

This study also has several strengths. We carefully adjusted for known individual and community factors that might be associated with mammography, and our statistical models reflected the nesting of individuals within communities. We used data broadly representative of the US population. Our models and hypotheses were grounded in theory derived from plausible mechanisms about the interplay between community factors and individual outcomes.

Long after the individual harms of tobacco use were well established, reductions in tobacco use received their biggest boost when evidence emerged that maternal smoking harms the fetus, and that passive inhalation of tobacco smoke harms nearby nonsmokers. Similarly, researchers have been amassing information about the individual harms of uninsurance, and now we are seeing increasing evidence that uninsurance hurts even the insured.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

AUTHOR CONTRIBUTIONS

Conception and design: José A. Pagán, David A. Asch, Cynthia J. Brown, Katrina Armstrong
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Acknowledgment

We thank José E. Olivares and Lakshmi Balasubramanian for providing excellent research assistance.

End-of-Life Medical Treatment Choices: Do Survival Chances and Out-of-Pocket Costs Matter?

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Background. *Out-of-pocket medical expenditures incurred prior to the death of a spouse could deplete savings and impoverish the surviving spouse. Little is known about the public's opinion as to whether spouses should forego such end-of-life (EOL) medical care to prevent asset depletion.* ***Objectives***. *To analyze how elderly and near elderly adults assess hypothetical EOL medical treatment choices under different survival probabilities and out-of-pocket treatment costs.* ***Methods***. *Survey data on a total of 1143 adults, with 589 from the Asset and Health Dynamics Among the Oldest Old (AHEAD) and 554 from the Health and Retirement Study (HRS), were used to study EOL cancer treatment recommendations for a hypothetical anonymous married woman in her 80s.* ***Results***. *Respondents were more likely to recommend treatment when it was financed by Medicare than by the patient's own savings and when it had 60% rather than 20% survival probability. Black and male respondents were more likely to recommend treatment regardless of survival probability or payment source. Treatment uptake was related to the order of presentation of treatment options, consistent with starting point bias and framing effects.* ***Conclusions***. *Elderly and near elderly adults would recommend that the hypothetical married woman should forego costly EOL treatment when the costs of the treatment would deplete savings. When treatment costs are covered by Medicare, respondents would make the recommendation to opt for care even if the probability of survival is low, which is consistent with moral hazard. The sequence of presentation of treatment options seems to affect patient treatment choice.* ***Key words:*** *end-of-life care; Medicare; heuristics and biases; oncology; willingness to pay.* ***(Med Decis Making 2008;28:511–523)***

Over the past 4 decades, the poverty rate of the US elderly population has fallen by more than 60%, and the most recent data (2005) show that only about 1 of every 10 people aged 65 and older (3.6 million) earned less than the poverty level.[1] Yet, the poverty rate of elderly widows is 3 times higher than that of elderly married women.[2] Recent studies provide convincing evidence that out-of-pocket health care expenditures incurred prior to the death of a spouse are partially responsible for the impoverishment of the surviving spouse.[3,4] As much as one fourth of the increase in elderly poverty after widowhood has been attributed to end-of-life (EOL) out-of-pocket health care expenditures.[2] This added financial burden may also be related to major depression and poorer health outcomes for elderly spousal caregivers.[5–7]

Although out-of-pocket medical expenditures prior to the death of a spouse can drive the surviving spouse into poverty, it is unclear from the literature whether people would and should forego expensive late-life medical care to prevent asset depletion. For example, an altruistic spouse may choose to forego expensive EOL medical care to protect assets to shield the widowed spouse from impoverishment or from a decline in living standards after widowhood.

There is also limited research on how individuals respond to changes in prognosis of life-threatening health conditions under different

Received 1 August 2006 from the Population Aging Research Center of the Population Studies Center (LWC, BJS) and Leonard Davis Institute of Health Economics (LWC, JAP), University of Pennsylvania, Philadelphia, Pennsylvania, and Department of Economics and Finance, College of Business Administration, University of Texas–Pan American, Edinburg, Texas (JAP). Financial support for the study was provided by the National Institutes of Health, National Institute on Aging (P30AG12836, B. J. Soldo, principal investigator). LWC was supported by a career award from the National Institutes of Health Fogarty International Center (K01TW06658). JAP was supported by the Department of Defense Breast Cancer Research Program (W81XWH-06–1-0334). Revision accepted for publication 1 October 2007.

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DOI: 10.1177/0272989X07312713

health care financing mechanisms and on their views as to whether policy choices for various treatment options should depend on prognosis and financing. For example, when would a terminally ill person agree to forego medical treatment that prolongs survival, and how is this decision modified under different survival probabilities and diverse cost scenarios? Would the same terminally ill person opt for treatment despite a low probability of success just because health insurance coverage results in low out-of-pocket cost?

The purpose of this study is to analyze the various EOL medical treatment choices that elderly and near elderly adults would recommend for a hypothetical elderly woman with cancer, when the treatment choices have varying probabilities of success and substantially different financial implications. To the extent that the recommendations are for a hypothetical person, the choices reflect the respondents' policy choices rather than choices for themselves.

METHODS

Data Source and Study Population

We used survey data from the Asset and Health Dynamics Among the Oldest Old Study (AHEAD) and the Health and Retirement Study (HRS)—which include identical experimental modules with various vignettes on EOL medical treatment—to study the AHEAD and HRS respondents' expressed recommendations for various hypothetical treatments for cancer. Prior to 1998, the AHEAD and HRS were separate but related surveys. The AHEAD included persons born in 1923 or before, and interviews were conducted in 1993 and 1995. The HRS included persons born from 1931 to 1941, and interviews were conducted in 1992, 1994, and 1996. The 2 surveys were merged starting in 1998 and are now known simply as the HRS, with interviews every 2 years since 1998. The vignettes used in our study came from the 1995 AHEAD and the 1996 HRS.

The original HRS included noninstitutionalized adults born from 1931 to 1941, who were selected from a nationally representative sample of US households that included oversamples of blacks, Hispanics, and Florida residents, using a multistage area probability sample design. The HRS was designed to follow age-eligible individuals and their spouses as they transition from active worker into retirement. Data collection through in-home, face-to-face interviews began in 1992 with a panel of 12,654 participants, with subsequent telephone reinterviews every 2 years thereafter.[8] The AHEAD study was designed as a supplementary sample to the HRS to examine health, family, and economic variables in the postretirement period and at the end of life. The first wave of AHEAD began in 1993 with a sample of 8222 participants, who were selected from the same nationally representative sample of US households as the original HRS but by selecting participants who were born in 1923 or before. Blacks, Hispanics, and Florida residents were also oversampled in the AHEAD study.[9] HRS and AHEAD both contain detailed information on demographics, health status, housing, family structure, employment, work history, disability, retirement plans, net worth, income, and health and life insurance. More detailed information on the design of the AHEAD and HRS surveys can be found on the data's Web site.[10]

Wave 2 of AHEAD (1995) and wave 3 of the HRS (1996) included a set of experimental questions that were asked to 605 and 556 randomly selected respondents of each study, respectively. Respondents listened to a vignette that asked them to consider the treatment choice for a hypothetical married woman in her eighties of unspecified race or ethnicity with a life-threatening form of cancer. Respondents were told that this woman would die within a few months if she did not undergo a treatment plan that could delay the spread of cancer. The treatment would make her dependent on personal care help during the treatment period. The treatment's probability of success was either low or high (20% or 60%), and the out-of-pocket treatment costs were also either low (with Medicare covering the costs) or high (with near depletion of household savings because Medicare would not cover the costs). All 4 combinations of success probabilities (low v. high) and out-of-pocket costs (low v. high) were presented in 4 different vignettes to the respondents. (The vignettes are reproduced at the bottom of Table 2; the vignettes and questions were identical in both the HRS and AHEAD studies.) Each respondent was randomly assigned to 1 of 4 groups. Every group received the same 4 vignettes, except the sequence with which the vignettes were presented was randomized by groups. Randomization of the vignette sequence was done because ordering effects could affect responses due to, for example, starting point bias or framing.[11]

Statistical Analysis

We employed nonparametric statistical tests in our bivariate comparisons. We used the within-group

Wilcoxon signed rank test to test for whether the respondent's opinion changed—on whether the hypothetical married woman should accept or reject the various treatment options—when different survival probabilities and financing mechanisms were presented in the 4 vignettes. To test for whether the distribution of the respondent's choices to the same vignette differed between groups of respondents (who were presented with different sequences of the vignettes), we used the Kruskal-Wallis test to compare between groups.[12]

We also analyzed the determinants of the respondent's propensity to recommend for or against the treatment options by using *ordered* logistic regressions. The dependent variables are the *thresholds* of survival probability or of financing options, or changes in these thresholds that the treatment would have to reach before the respondents would agree to recommend that the woman in the vignette accept treatment. These thresholds or cutoff values in the ordered logistic regressions come from the probabilities and financing options specified in the vignettes; they are noted at the bottom of Table 5 and described in detail in the results section for that table. The explanatory variables included the respondent's age, education, and net household wealth as continuous variables, as well as marital status, gender, race or ethnicity, health status, health status of the spouse if married, past experience with cancer, and religion as dummy variables. Because the HRS and the AHEAD subsamples come from different cohorts that may have differing viewpoints (in addition to age), we included a dummy indicator for the AHEAD cohort. We also included dummy variables for the randomized sequence groups to examine whether the order in which the 4 vignettes were presented was related to the respondents' opinions.

RESULTS

From the original 1161 respondents who were randomized into the cancer treatment experimental module, we excluded 18 who had missing values for our core set of explanatory variables, leaving us with 1143 observations (with 554 from HRS and 589 from AHEAD). No respondent was excluded based on answers to the cancer treatment experimental module because everyone assigned to the module gave some form of response to these questions. Descriptive statistics of the sample are shown in Table 1. There were no significant differences in demographic and socioeconomic characteristics across the 4 randomized sequence groups (evaluated using chi-square tests not shown in the table).

Table 1 Descriptive Statistics of the Sample

Variable	Mean or Percentage
Male, %	38.50
Non-Hispanic white/other, %	85.30
Non-Hispanic black, %	12.07
Hispanic, %	2.62
Married, %	68.15
Respondent in poor/fair health, %	23.27
Spouse in poor/fair health, % among those married	23.62
Respondent has/had cancer, %	12.51
Protestant religion, %	68.85
Catholic religion, %	22.13
AHEAD cohort, %	51.53
Age, years	68.25
Education, years	12.26
Household wealth, US$ 100,000	2.99
Sample size	1143

AHEAD, Asset and Health Dynamics Among the Oldest Old Study.

To simplify our discussion below, the verbatim transcripts of the 4 vignettes are reproduced at the bottom of Table 2. Although most respondents gave answers of yes or no to the vignettes, some respondents answered "don't know" or "depends" or "refused to answer" some of the vignettes. About 9% of respondents gave these other-than-yes-or-no answers for vignette S60, and such answers were slightly less prevalent for the other vignettes, with 6.9%, 7.4%, and 6.5% for vignettes M20, M60, and S20, respectively. For the subsequent analyses, we decided to collapse these other answers with the "no" answer while keeping "yes" as a separate category for 3 reasons: 1) because our main research question ("whether people should forego care to prevent impoverishment") required the combined information from multiple vignettes, modeling these other answers as separate choices would quickly explode the number of parameters in a multinomial logit, making interpretation of results exceedingly complex; 2) although there are no tests available[13] for whether categories could be combined in an *ordered* logistic regression model (a model that we use to capture the natural order of survival probabilities or of financing options in the combined vignettes), we ran multinomial logits using each vignette individually, and the likelihood ratio tests[14] of whether these other answers could be combined with either yes or no answers rejected the null for

Table 2 Percentage Agreeing to Hypothetical Cancer Treatment, Grouped by Vignette Sequence

(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)
				Group by Sequence of Vignettes				*P* Value
Treatment Vignettes	Financing Mechanism	Survival Probability	Full Sample	Group 1	Group 2	Group 3	Group 4	Difference across Groups
M20	Medicare	20%	37.10	44.98 [1]	33.94 [2]	39.79 [3]	29.51 [4]	0.001
M60	Medicare	60%	58.01	62.63 [2]	54.87 [1]	60.90 [4]	53.47 [3]	0.070
S20	Savings	20%	26.51	32.18 [3]	25.62 [4]	27.68 [1]	20.49 [2]	0.015
S60	Savings	60%	42.17	47.06 [4]	41.16 [3]	47.06 [2]	33.33 [1]	0.002
Percentage of sample			100	25.28	24.23	25.28	25.20	

Descriptions of Vignettes

M20: "Now I'd like to describe a specific situation and get your opinion about it. Here is the situation: A married woman in her 80s is told by her doctor that she has a life-threatening form of cancer. The doctor tells her that without any treatment she is likely to die within the next few months. He describes a 4-month treatment plan aimed at delaying the spread of the cancer. The treatment itself would make her fairly uncomfortable, and she would have to rely on others for personal care during the treatment. The treatment costs are fairly high but Medicare will pay most of the costs. The doctor tells her that, with the treatment, she stands a 20% chance of living 2 or 3 good years after completing the treatment. Do you think she should agree to the treatment?"

M60: "What if the doctor had, instead, told her that with the treatment, she stood a 60% chance of living 2 or 3 good years? Do you think she should agree to the treatment then?"

S20: "Now let's say the situation is a bit different. The same woman faces the same decision whether to agree to the same 4-month treatment for her cancer, but this time instead of Medicare paying most of the costs, she and her husband will have to pay most of the costs. They could afford to do so but it would take almost all of their savings. The doctor tells her that, with the treatment, she stands a 20% chance of living 2 or 3 good years after completing the treatment. Do you think she should agree to the treatment?"

S60: "What if the doctor had, instead, told her that with the treatment, she stood a 60% chance of living 2 or 3 good years? Do you think she should agree to the treatment then?"

Number in brackets denotes the sequence of vignettes for each group; *P* value by Kruskal-Wallis test.

combining with "yes" in 4 out of 4 vignettes (*P* values from < 0.0001 to 0.03) and failed to reject the null for combining with "no" for vignettes S60 and M60 (although S20 and M20 were rejected at *P* values less than 0.05); and 3) regardless of whether we combined these other answers with no or with yes answers, our main results and conclusions do not change.

The top panel of Table 2 summarizes the decisions made by the respondents in the 4 different groups. Each group had a different sequence of how the treatment vignettes were presented, with the 4 possible combinations of financing source (Medicare v. savings) and treatment success (20% v. 60%) making up the 4 groups. Column 1 presents the codes we used for each of the 4 possible vignettes to indicate the financing mechanism (column 2) and the survival probability (column 3). In column 1, "M" denotes Medicare financed, "S" denotes savings financed, "20" denotes 20% treatment success, and "60" denotes 60% treatment success.

Column 4 presents the acceptance rates for the 4 treatment vignettes as recommended by the full sample. The rankings of the percentages of respondents in favor of treatment for the 4 vignettes were consistent with a priori expectations. The percentage of respondents who would recommend accepting S20, the vignette when the treatment had to be financed out of the patient's own savings and had only a 20% survival chance, was far lower than the percentage who would favor M60, the vignette where the treatment was financed by Medicare and the survival chance was 60%, with the acceptance rates for the other 2 vignettes falling between the 2 extremes.

Columns 5 to 8 in Table 2 report the percentage of respondents who agreed that the married woman in the vignette should undergo cancer treatment,

Table 3 Number (and Percentage) of Respondents, by Latent "Reservation" Survival Probability

Minimum Survival Probability Threshold Required before Recommending Accepting Treatment						
Conditional on Financing by Medicare			Conditional on Financing by Patient's Own Savings			
			Less Than 20% Survival (S20 = 1; S60 = 1)	20% to 60% Survival (S20 = 0; S60 = 1)	More Than 60% Survival (S20 = 0; S60 = 0)	Total by Row
(0)			(1)	(2)	(3)	(4)
(1)	Less than 20% survival	(M20 = 1; M60 = 1)	303 (26.5%)[a]	62 (5.4%)[b]	59 (5.2%)[c]	424 (37.1%)
(2)	20% to 60% survival	(M20 = 0; M60 = 1)	0	117 (10.2%)[d]	122 (10.7%)[e]	239 (20.9%)
(3)	More than 60% survival	(M20 = 0; M60 = 0)	0	0	480 (42.0%)[f]	480 (42.0%)
Total by column			303 (26.5%)	179 (15.7%)	661 (57.8%)	1143 (100%)

Superscripts denote the respondents' accept/reject decisions for the 4 vignettes, with 1 = accept and 0 = reject as follows:
a. M20 = 1, M60 = 1, S20 = 1, S60 = 1.
b. M20 = 1, M60 = 1, S20 = 0, S60 = 1.
c. M20 = 1, M60 = 1, S20 = 0, S60 = 0.
d. M20 = 0, M60 = 1, S20 = 0, S60 = 1.
e. M20 = 0, M60 = 1, S20 = 0, S60 = 0.
f. M20 = 0, M60 = 0, S20 = 0, S60 = 0.

tabulated by vignette and by group. The ordering in which the vignettes were presented to the respondents is indicated by the number inside the brackets in Table 2. For instance, group 2 received the vignettes in the sequence of M60, M20, S60, and S20, and group 3 received S20, S60, M20, and M60. As a very rough approximation, group 2 respondents received vignettes in a descending order of potential value, and group 3 received vignettes in an ascending order of potential value.

The acceptance rate for the various vignettes differed across the groups, reaching statistical significance for 3 out of the 4 vignettes (column 9). Because the respondents were randomized into the 4 groups, this significant difference across groups suggests that the recommendation to accept or reject the hypothetical treatment was related to the sequence with which the vignettes were presented.

The 4 vignettes varied on 2 dimensions: financing and survival probability. Because the respondents were given discrete choices (yes or no) to the treatment in the vignettes, we do not observe the true underlying latent variables that form the decision basis for the respondents. Instead, we observe the various cutoff points that actually could serve as bounds (or thresholds) for the latent variables. The cutoff points for financing are near depletion of the patient's savings v. low financial cost, and for survival, 20% and 60%. Under the 2 vignettes when Medicare covers the treatment costs, the financing variable is fixed (low financial cost), but the survival probability variable is varied. Therefore, *conditional on Medicare paying for the treatment*, the respondents' recommendations under the 2 survival probabilities essentially reflect the respondents' latent "reservation" survival probability or, equivalently, the minimum survival probability the respondents feel that the treatment must provide the patient in order for the respondents to recommend that the patient accept the treatment. When the respondents recommend accepting treatment at 20% survival probability, the respondents' reservation survival probability is less than or equal to 20%; when the respondents reject treatment at 20% but accept when survival is 60%, the respondents' reservation survival probability is between 20% and 60%. These are depicted in Table 3. Column 0 tabulates the possible decisions when survival probability changes from 20% to 60% but *conditional on financing by Medicare*. Conditional on Medicare paying for the costs, respondents could recommend to 1) accept treatment with 20% or 60% survival probability (coded M20 = 1; M60 = 1), 2) reject the treatment with 20% but accept the treatment with 60% survival (coded M20 = 0; M60 = 1), or 3) reject treatment even with a 60% survival (coded M20 = 0; M60 = 0). The first kind of respondents has a latent reservation survival probability for the patient (*conditional on* Medicare coverage) that is less than 20% because they would

recommend that the patient accept treatment with a 20% survival. The second kind of respondents has a latent reservation survival probability for the patient between 20% and 60%. The third kind of respondents has a latent reservation survival probability for the patient that is higher than 60% because they would recommend that the patient reject the treatment even when it offered 60% survival for the patient.

Similarly, columns 1, 2, and 3 in Table 3 present the possible acceptance/rejection recommendations under varying survival probability but *conditional on financing by the patient's own savings*. Conditional on having the patient pay for the treatment out of her household savings, respondents could recommend to 1) accept treatment when it has a 20% survival probability (coded S20 = 1; S60 = 1), 2) reject if the treatment has 20% survival but accept if it has 60% survival (coded S20 = 0; S60 = 1), or 3) reject even when the treatment has 60% survival (coded S20 = 0; S60 = 0).

The cells in Table 3 present the number and percentage of respondents who gave the various treatment recommendations under different survival probabilities—and conditional on the treatment being financed either by Medicare or by the patient's own savings. The superscript letters in the cells denote the respondents' choices to the 4 vignettes, as explained in the note at the bottom of the table. When Medicare covers the treatment costs, a total of 424 respondents have a less than 20% reservation survival probability for the patient (shown in row 1 or cells a, b, and d of Table 3). They would recommend that the patient accept the treatment when survival is 20%. However, when treatment has to be financed by the patient's own savings, these same respondents' reservation survival probability for the patient shifts higher, so that some respondents require the treatment to have a higher survival probability before they would recommend that the patient in the vignette accept the treatment. Thus, when the patient had to pay for the treatment, 303 respondents (cell a) still had a reservation survival probability for the patient of less than 20%, 62 respondents (cell b) required a higher reservation survival probability of between 20% and 60%, and 59 respondents (cell d) had a reservation survival probability greater than 60%. Similarly, when Medicare covers the costs, a total of 239 respondents had a reservation survival probability between 20% and 60% (in row 2 or cells c and e of Table 3). However, when the treatment costs had to be covered by the patient's own savings, 122 out of the original 239 respondents would recommend rejecting treatment with a 60% survival, suggesting that their reservation survival probability for the patient was higher than 60%. Therefore, when financing changed from Medicare to the patient's own savings, respondents in cells a, c, and f would continue to recommend the same treatment, but respondents in cells b, d, and e would recommend rejecting the same treatment because such treatment no longer met their higher reservation survival probability for the patient. Thus, a total of 243 or 21% of the respondents rejected the same treatment when financing changed from Medicare to savings depletion.

Table 4 presents the minimum level of patient wealth that the respondent feels the patient must retain to recommend that the patient accept the treatment, *conditional on survival probability*. In column 0, *conditional on 60% survival*, the respondents could recommend to 1) accept treatment when it is financed by the patient's own savings, 2) reject treatment when savings financed but accept if Medicare financed, or 3) reject treatment even when Medicare financed. The first type of respondents has a very low reservation wealth for the patient because they would rather see that the patient deplete savings and opt for the treatment at 60% survival than to have the patient maintain her current wealth but receive no treatment. The second type has a reservation wealth level for the patient that is between asset depletion and the patient's current wealth. The third type has a reservation wealth level for the patient that is more than the patient's current wealth; these respondents feel that the patient must be *paid* before the respondents would recommend that the patient accept treatment with a 60% survival probability. The cells in Table 4 tabulate the number and percentages of respondents who fall into each of the 3 latent reservation wealth levels, but conditioning on 20% or 60% survival.

To find out the covariates that are related to the latent reservation survival or wealth levels, we performed a series of ordered logistic regressions using the survival or wealth latent variable as the dependent variable and various sociodemographic and health variables as explanatory variables. The results are shown in Table 5.

The dependent variables for columns 2 through 5 are the reservation thresholds. In columns 2 and 3, for instance, the dependent variables are the reservation survival probability thresholds, with cutoffs at 20% and 60%, conditional on, respectively, Medicare financing and patient savings financing. The dependent variables in columns 4 and 5 consist of

Table 4 Number (and Percentage) of Respondents, by Latent "Reservation" Wealth Level

Minimum Wealth (or Financing) Threshold Required before Recommending Accepting Treatment					
Conditional on 60% Survival		Conditional on 20% Survival			
		< Savings Depletion (S20 = 1; M20 = 1)	Savings Depletion to Current Wealth (S20 = 0; M20 = 1)	> Current Wealth (S20 = 0; M20 = 0)	Total by Row
(0)		(1)	(2)	(3)	(4)
(1) < Savings depletion	(S60 = 1; M60 = 1)	303 (26.5%)[a]	62 (5.4%)[b]	117 (10.2%)[c]	482 (42.2%)
(2) Savings depletion to current wealth	(S60 = 0; M60 = 1)	0	59 (5.2%)[d]	122 (10.7%)[e]	181 (15.8%)
(3) > Current wealth	(S60 = 0; M60 = 0)	0	0	480 (42.0%)[f]	480 (42.0%)
Total by column		303 (26.5%)	121 (10.6%)	719 (62.9%)	1143 (100%)

Superscripts denote the respondents' accept/reject decisions for the 4 vignettes, with 1 = accept and 0 = reject as follows:
a. M20 = 1, M60 = 1, S20 = 1, S60 = 1.
b. M20 = 1, M60 = 1, S20 = 0, S60 = 1.
c. M20 = 0, M60 = 1, S20 = 0, S60 = 1.
d. M20 = 1, M60 = 1, S20 = 0, S60 = 0.
e. M20 = 0, M60 = 1, S20 = 0, S60 = 0.
f. M20 = 0, M60 = 0, S20 = 0, S60 = 0.

the reservation wealth thresholds, with cutoffs at patient savings depletion and the patient's current wealth, conditional on, respectively, 60% and 20% survival. For all the reservation thresholds, male and black respondents stood out as having a much lower odds of having a high reservation threshold for the patient, suggesting that they had low reservation levels for both the survival and wealth variables. In other words, they are more likely to recommend that the patient accept treatment, regardless of survival probability or financing source. Under Medicare financing (column 2), married respondents (whose spouses were not in poor health) were more likely than those not married to recommend that the patient accept treatment, although such a differential effect was not significant when the treatment entailed depletion of the patient's savings (column 3). The respondent's health or prior history of cancer did not seem to matter in the treatment recommendations; however, married respondents with spouses in poor health were far more likely to recommend accepting treatment than those who were married but whose spouses were not in poor health.[15] Respondent's age, household wealth, education, and religion did not seem to matter. The AHEAD dummy variable was also insignificant, including in separate regressions without the age variable (not reported in the table).

The respondent's sequence group was also included as dummy variables to control for the effect from vignette ordering, with group 2 as the reference. Group 2 was the one where the vignettes were presented in a sequence suggestive of decreasing potential value (M60, M20, S60, S20). Conditional on financing, group 2's vignette sequence suggested a loss in survival (going from 60% to 20%, under each financing scheme). Conditional on financing, groups 1 and 3 both had a sequence of vignettes that were increasing in survival. Under Medicare financing (column 2), group 1 and group 3 had lower reservation survival probability than group 2 at $P < 0.01$ and $P < 0.10$, respectively, indicating that the respondents who experienced a sequential loss in survival (group 2) needed a higher survival probability to "compensate" for the loss *more than* the respondents who experienced a sequential gain in survival (groups 1 and 3). Conditional on savings-financed care (column 3), group 1 continued to have a lower reservation survival probability threshold than group 2. Under savings financing (column 3), group 4 had a higher reservation survival probability than group 2, probably because the sequential loss in survival probability was more salient in group 4 (which had savings financing presented before Medicare financing). The S60 and S20 vignettes were presented to group 2 respondents after they had received the first set of vignettes that included Medicare coverage. Therefore, there is some evidence of an ordering effect that is related to the sequence with which the vignettes were presented. Our simple dummy variable for group, however, limits our ability to explain more fully the underlying reasons for the ordering effect.

Table 5 Adjusted Odds Ratios from Ordered Logistic Regressions

Explanatory Variables	Odds Ratios for Having a Higher Level of Reservation Threshold								Odds Ratios of an Increase in Reservation Threshold	
	Conditional on Financing by Medicare		Conditional on Financing by Patient's Savings		Conditional on 60% Survival Probability		Conditional on 20% Survival Probability		When Financing Changes from Medicare to Own Savings	
(1)	(2)		(3)		(4)		(5)		(6)	
	Odds Ratios	95% CI	Odds Ratios	95% CI	Odds Ratios	95% CI	Odds Ratios	95% CI	Odds Ratios	95% CI
Male	0.61	(0.47, 0.77)**	0.53	(0.41, 0.68)**	0.56	(0.44, 0.72)**	0.60	(0.46, 0.78)**	0.64	(0.46, 0.91)*
Black	0.26	(0.18, 0.38)**	0.24	(0.17, 0.35)**	0.27	(0.18, 0.40)**	0.23	(0.16, 0.34)**	0.53	(0.31, 0.90)*
Hispanic	0.70	(0.35, 1.42)	1.25	(0.57, 2.75)	1.00	(0.49, 2.03)	0.73	(0.34, 1.56)	2.87	(1.15, 7.13)*
Married	0.75	(0.56, 1.00)*	0.84	(0.62, 1.14)	0.83	(0.62, 1.11)	0.71	(0.51, 0.97)*	1.07	(0.70, 1.63)
Respondent in poor/fair health	1.02	(0.77, 1.34)	0.98	(0.73, 1.31)	0.98	(0.74, 1.30)	1.01	(0.74, 1.37)	0.93	(0.61, 1.40)
Spouse in poor/fair health	0.65	(0.47, 0.90)**	0.67	(0.48, 0.94)*	0.72	(0.52, 1.00)*	0.61	(0.43, 0.86)**	0.92	(0.59, 1.44)
Respondent has/had cancer	1.23	(0.87, 1.73)	1.22	(0.84, 1.76)	1.24	(0.88, 1.76)	1.17	(0.79, 1.72)	1.18	(0.71, 1.98)
Protestant	1.00	(0.67, 1.48)	0.86	(0.57, 1.32)	0.95	(0.64, 1.42)	0.92	(0.59, 1.42)	0.78	(0.44, 1.35)
Catholic	0.86	(0.55, 1.34)	0.75	(0.47, 1.20)	0.86	(0.55, 1.35)	0.76	(0.46, 1.24)	0.90	(0.48, 1.68)
AHEAD	0.74	(0.49, 1.12)	0.98	(0.63, 1.51)	0.83	(0.55, 1.25)	0.89	(0.57, 1.40)	1.97	(1.07, 3.64)*
Age	1.00	(0.98, 1.02)	1.00	(0.98, 1.02)	1.00	(0.98, 1.02)	0.99	(0.97, 1.01)	0.98	(0.95, 1.01)
Education	1.00	(0.96, 1.05)	1.00	(0.95, 1.04)	0.99	(0.95, 1.03)	1.01	(0.97, 1.06)	1.00	(0.94, 1.06)
Household wealth	1.00	(0.98, 1.01)	1.00	(0.98, 1.01)	0.99	(0.98, 1.01)	1.00	(0.98, 1.02)	1.00	(0.98, 1.03)
Group 1	0.64	(0.47, 0.88)**	0.71	(0.51, 0.99)*	0.71	(0.52, 0.98)*	0.62	(0.44, 0.87)**	1.24	(0.77, 1.99)
Group 3	0.74	(0.54, 1.02)	0.79	(0.57, 1.10)	0.76	(0.55, 1.04)	0.79	(0.55, 1.11)	1.17	(0.73, 1.88)
Group 4	1.17	(0.85, 1.61)	1.50	(1.06, 2.11)*	1.26	(0.92, 1.74)	1.36	(0.94, 1.95)	1.77	(1.10, 2.86)*
Accept 20% Survival with Medicare									0.60	(0.43, 0.84)**
Sample size	1143		1143		1143		1143		663	
Likelihood ratio										
Chi-square	99.90		107.94		90.33		110.55		49.96	
df	16		16		16		16		17	
P level	< 0.0001		< 0.0001		< 0.0001		< 0.0001		< 0.0001	
Adjusted *R*-square	0.10		0.11		0.09		0.11		0.09	
Test for proportional odds assumption										
Chi-square	23.66		26.30		21.21		19.94		145.94	
df	16		16		16		16		17	
P level	0.10		0.05		0.17		0.22		< 0.0001	

(continued)

Table 5 (continued)

Explanatory Variables	Odds Ratios for Having a Higher Level of Reservation Threshold								Odds Ratios of an Increase in Reservation Threshold	
	Conditional on Financing by Medicare		Conditional on Financing by Patient's Savings		Conditional on 60% Survival Probability		Conditional on 20% Survival Probability		When Financing Changes from Medicare to Own Savings	
(1)	(2)		(3)		(4)		(5)		(6)	
	Odds Ratios	95% CI	Odds Ratios	95% CI	Odds Ratios	95% CI	Odds Ratios	95% CI	Odds Ratios	95% CI
Variables in *partial* proportional odds model that are significantly different from those in the regular proportional odds model										
Group 4 (low/medium v. high threshold)	0.29	(0.18, 0.46)**							1.06	(0.43, 2.61)
Group 4 (low v. medium/high threshold)	0.24	(0.16, 0.36)**	(no variables with		(no variables with		(no variables with		0.55	(0.32, 0.94)*
AHEAD (low/medium v. high threshold)	0.83	(0.55, 1.26)	$P < 0.10$)		$P < 0.10$)		$P < 0.10$)			
AHEAD (low v. medium/high threshold)	0.66	(0.43, 1.00)*								
Hispanic (low/medium v. high threshold)									6.11	(1.94, 19.19)**
Hispanic (low v. medium/high threshold)									2.03	(0.75, 5.51)

The dependent variables for these ordered logistic regressions are the various reservation thresholds as bounded by the cutoffs in the vignettes and are coded as follows. For columns 2 and 3: "reservation survival probability less than 20%" = 1; "reservation survival between 20% and 60%" = 2; "reservation survival above 60%" = 3. For columns 4 and 5: "reservation wealth level less than savings depletion" = 1; "reservation wealth between savings depletion and current wealth" = 2; "reservation wealth > current wealth" = 3. For column 6: "no shift in reservation survival" = 1; "shift from less than 20% to 20% to 60% or shift from 20% to 60% to greater than 60%" = 2; "shift from less than 20% to greater than 60%" = 3. CI, confidence interval; AHEAD, Asset and Health Dynamics Among the Oldest Old Study.

*$P < 0.05$. **$P < 0.01$.

One question we set out to answer was whether people would recommend as part of health policy that the hypothetical woman in the vignettes forego breast cancer treatment that potentially entailed impoverishing herself or her spouse. A corollary question, then, is whether those who recommended that the patient accept treatment under Medicare financing would recommend that the patient forego treatment when the treatment had to be financed by the patient's own savings. The answer is a resounding yes, among many of the respondents. This is depicted in Table 3, where the respondents are classified into different cells of the table with different superscript letters, based on whether they would recommend accepting or rejecting treatment with different financing and survival (as defined in the note at the bottom of Table 3). Respondents in the cells along the diagonal did not change their recommendation when financing changed from Medicare to the patient's own savings. Respondents off the diagonal, however, changed their recommendations when financing changed from Medicare to the patient's savings. Those in cell b recommended that the patient accept treatment with a 20% survival when it was Medicare financed but recommended that the patient reject treatment when it had the same 20% survival but had to be financed by the patient's savings; under patient savings financing, these same respondents recommended that the patient accept the treatment when the survival was higher at 60%. Respondents in cell d recommended the treatment with 20% survival when Medicare financed but rejected treatment even with 60% survival when patient savings financed. Respondents in cell e rejected treatment at 20% survival even when it was Medicare financed, accepted it when survival was 60% and Medicare financed, but rejected it when the treatment had 60% survival but had to be self-financed by the patient. Therefore, respondents in the off-diagonal cells (b, d, and e) switched their recommendations when financing changed from Medicare to the patient's own savings.

One relevant question is who would be more likely to switch recommendations when the financing switched from Medicare to the patient's own savings. Column 6 in Table 5 shows the results from an ordered logistic regression of the determinants of the *changes* in the respondent's reservation survival probability thresholds when financing changed from Medicare to the patient's own savings (having controlled for baseline choice). Column 6 compares those who switched treatment recommendations (thus implying a shift in reservation survival probability thresholds when financing switched from Medicare to the patient's own savings) with those who did not switch—by comparing the characteristics of respondents who fall into cells b, c, and e v. those in cells a and d of Table 3. Because the respondents in cell f of Table 3 already recommended that the patient reject treatment under Medicare and were not able to switch their answers when the financing switched to the patient's own savings, we deleted these respondents in the regression. Furthermore, because respondents in rows 2 and 3 of Table 3 differed in their baseline reservation thresholds (and thus their recommendations) under Medicare financing, we included a dummy variable "accept 20% survival with Medicare financing" to the regression in column 6 of Table 5.

The results of this regression show that male and black respondents were far less likely to switch treatment recommendations even if it meant depleting the patient's own savings. Interestingly, Hispanic respondents were far more likely to change their minds (than whites and blacks) and to recommend that the patient opt out of treatment when financing for the treatment changed from Medicare to the patient's own savings. Respondents in the AHEAD cohort were more likely to opt out as well, having controlled for age. Finally, marital status, health status, spouse's health status, cancer history, education, and household wealth were not significant determinants of switches in treatment recommendations when financing changed from Medicare to the patient's savings.

Because ordered logistic regression models make the proportional odds assumption,[16] we tested and corrected for this violation with a series of ordered logistic regressions using *partial* proportional odds models. The variables that differed significantly between proportional odds and partial proportional odds models are presented in the bottom panel of Table 5. Our main findings do not change with the less restrictive partial proportional odds models. In fact, the only difference in the odds ratios pertains to the size rather than the direction of the effect. The only nontrivial size difference was the odds of Hispanics switching from accepting to rejecting treatment when financing changed from Medicare to patient savings (column 6 of Table 5), with the original odds ratio of 2.79 (from the proportional odds model) increasing to 5.46 (with the partial proportional odds model); this reflects the fact that most Hispanics who recommended accepting Medicare-financed treatment

at 20% survival switched to rejecting the treatment even at 60% survival when the treatment had to be financed by the patient's savings.

DISCUSSION

With a unique data set that included elderly and near elderly respondents in the United States and their answers to a set of vignettes about end-of-life health care treatment decisions on behalf of a hypothetical elderly woman, we explored how elderly and near elderly adults assess EOL medical treatment choices with varying probabilities of success and with substantially different financial implications. Before we discuss some of the main results and implications, we shall first highlight the limitations of our study, so that the results can be interpreted in light of these limitations.

Our study suffers from 2 main limitations. First, the respondents were asked about their opinion on cancer treatment choices for an anonymous, *hypothetical* woman in her 80s of unknown race or ethnicity. Although the answers should reflect the respondents' health policy choices, it is unclear whether some respondents also answered these vignettes taking the perspective of making the treatment choices for themselves or their spouse, rather than for a hypothetical person. Decisions based on the respondent's own life compared with that of a hypothetical person will likely depend on the emotional context, financial status, or other personal factors. We have controlled for some of these effects by including a set of demographic covariates, but our statistical analyses have not fully accounted for all the factors related to actual v. hypothetical answers that would bias our results.

Another important limitation to our study is that the respondents may have had difficulty in fully understanding the rather complex vignettes used to collect the data. For instance, the vignettes used 20% and 60% as survival probabilities, and some respondents may have had trouble interpreting probabilities. The way the vignettes were presented to the respondents also does not necessarily reflect how physicians normally convey information for treatment choices. In fact, physicians do not have uniform methods of presenting outcomes and uncertainty. Differences in the framing of outcomes (survival v. mortality, for instance) and the level of uncertainty (relative risk reduction, number of people needed to treat, probabilities) have both been shown to result in different treatment choices.[17] Although the literature recommends presenting information using multiple modalities, using charts, graphs, and simple heuristics (such as using 1-in-10 instead of 10% probability), there is no consensus about how best to present these kinds of information even during the "informed consent" process.[18] Clearly, more research is needed in this important part of physician-patient clinical decision making, especially when physicians themselves are also influenced by framing and the way risk and uncertainty are presented.[19]

In view of these limitations, our study does have some interesting although sometimes perplexing findings. We found that many respondents would recommend foregoing costly EOL treatments for a hypothetical woman in a set of vignettes when the treatment cost would wipe out the patient's savings. Among the total of 663 respondents who would recommend opting for care when it was financed by Medicare (cells a, b, c, d, and e in Table 3), 243 (or 36.7% of them; cells b, d, and e in Table 3) would not recommend accepting the same treatment if the woman in the vignette had to deplete savings to pay for the treatment. These numbers indicate that when treatment cost is not covered by Medicare, the respondents feel that the patient must be "compensated" with a higher treatment survival probability for them to recommend accepting treatment. Viewing this from an alternative angle, when treatment cost is covered by Medicare, respondents would recommend opting for care that even had a low survival probability. This latter phenomenon is the well-studied and well-documented moral hazard,[20] which essentially says that people will consume more care when the out-of-pocket cost is low.

Although it seems self-evident that people would be more likely to recommend opting for treatment if the patient's out-of-pocket costs were low, it is interesting that many of the respondents would recommend against treatment even when it entailed a low financial cost to the patient (e.g., respondents in cell f in Table 3). This may reflect concerns about various direct, indirect, and intangible costs related to the treatment. The vignettes state that Medicare will pay *most* of the costs, and as such, respondents may believe that the patient's out-of-pocket costs would still be significant even under the Medicare financing option because it does not cover *all* of the costs. The vignettes also indicated that the subject "would have to rely on others for personal care during the treatment." Nonmonetary costs associated with

caregiving and the monetary costs of hiring a caregiver may be important in actual treatment decisions.[21] In addition to these direct medical and nonmedical costs, there is also the pain and suffering associated with the treatment. However, it is difficult to assess how these costs induced any type of response bias. For instance, in terms of the pain and suffering, respondents with a history of cancer did not differ in their recommendations from those who have never had cancer (see Table 5).

Our study also found that black respondents were far more likely to recommend opting for treatment regardless of survival probability or payment source, a finding consistent with many prior studies.[22] White respondents were more likely to recommend opting out of care if that care meant depletion of the patient's savings. Interestingly, Hispanics were even more likely than whites to recommend opting out of such care; their treatment recommendations were the most sensitive to change in how the treatment would be financed. This finding needs to be further explored in other data sets because as far as we know, this has not been documented in the literature.

We also found that women were far more likely than men to switch out of treatment that they had recommended accepting under Medicare financing but now had to be paid out of the patient's pocket. In separate regressions stratified by marital status (not reported in the tables), this gender differential was significant only among married respondents; that is, married women were much more likely to recommend switching out of treatment when Medicare no longer paid, but women who were not married were not significantly more likely than unmarried men to recommend switching out of treatment. Many reasons are possible why there is this strong gender differential in recommendations. The vignettes asked about an elderly married woman with a threatening form of cancer needing treatment, and it is possible that the respondents were more altruistic than selfish: married male respondents might have identified more with the husband in the vignettes and felt that the wife should get care even if it meant impoverishing the patient's husband, but married female respondents might have identified more with the woman in the vignette and felt that the patient herself should forego care to prevent impoverishing her spouse. Willingness-to-pay studies among couples where one spouse has mild to moderate dementia and the other spouse is a caretaker have found evidence of altruism motives between the dyad.[23] One way to further study this treatment recommender v. treatment recipient gender effect would be to randomize the gender of the cancer patient in the hypothetical vignettes in future research. Another possible reason for the gender differential is that men might be more aggressive than women in opting for medical treatments, as in treatments for coronary artery disease.[24] In regressions not reported in the tables, we included a proxy for risk aversion for the HRS subsample, but it was not significant in any of the regressions, suggesting that any aggressiveness in opting for treatment among men was not due to risk tolerance. Despite our inability to test for the various reasons for this gender differential, further research is needed on this issue because it could have important welfare and policy implications. Given that women and men differed in their recommendations in these vignettes, the use of spouses as durable powers of attorney to make EOL care decisions should be further examined because women and men clearly had different preferences. This is an additional piece of evidence that discordant decisions could be likely even with advance directives.[25]

Finally, we found that the order in which the various treatment options were presented had an effect on the recommendation of uptake for the treatment. The ordering effect could be due to starting point bias in that the respondents latched onto their first answer as the framework to answer the subsequent vignettes. The respondents could also have been affected by framing. Each vignette was framed with both gain and loss: the survival probability was framed as a gain, and the financing was framed as a loss. Prior research has found that framing had an impact on the patient's decisions.[11] Moreover, in going from one vignette to the next, the sequence of vignettes was presented as gains, losses, or some combination of the two. Prior studies have documented ordering effects in willingness to pay for medical care for the public, but starting point bias and framing were found not to be dominant explanations.[26] The vignettes in our data were much more personal and asked the respondents to make a specific treatment choice for a woman in the vignette. Some of our findings do suggest that framing (in terms of whether the sequence of vignettes was presented as losses or gains across the vignettes) was a potential explanation for some of the ordering effect. The complexity of the vignettes and of their sequences of presentation, however, prevented us from further exploring the reasons for the ordering effect. Nevertheless, future research on ordering effects and their clinical relevance is warranted.

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Effect of Guidelines on Primary Care Physician Use of PSA Screening: Results from the Community Tracking Study Physician Survey

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Background. *Little is known about the effect of guidelines that recommend shared decision making on physician practice patterns. The objective of this study was to determine the association between physicians' perceived effect of guidelines on clinical practice and self-reported prostate-specific antigen (PSA) screening patterns.* ***Methods.*** *This was a cross-sectional study using a nationally representative sample of 3914 primary care physicians participating in the 1998–1999 Community Tracking Study Physician Survey. Responses to a case vignette that asked physicians what proportion of asymptomatic 60-year-old white men they would screen with a PSA were divided into 3 distinct groups: consistent PSA screeners (screen all), variable screeners (screen 1%–99%), and consistent nonscreeners (screen none). Logistic regression was used to determine the association between PSA screening patterns and physician-reported effect of guidelines (no effect v. any magnitude effect).* ***Results.*** *Only 27% of physicians were variable PSA screeners; the rest were consistent screeners (60%) and consistent nonscreeners (13%). Only 8% of physicians perceived guidelines to have no effect on their practice. After adjustment for demographic and practice characteristics, variable screeners were more likely to report any magnitude effect of guidelines on their practice when compared with physicians in the other 2 groups (adjusted odds ratio = 1.73; 95% confidence interval = 1.25−2.38; P = 0.001).* ***Conclusions.*** *Physicians who perceive an effect of guidelines on their practice are almost twice as likely to exhibit screening PSA practice variability, whereas physicians who do not perceive an effect of guidelines on their practice are more likely to be consistent PSA screeners or consistent PSA nonscreeners.* ***Key words:*** *prostate-specific antigen; mass screening; guidelines; physicians' practice patterns.* ***(Med Decis Making 2008;28:681–689)***

Clinical practice guidelines are "systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances."[1] Clinical practice guidelines have been shown to influence practice in settings where the guidelines have clear recommendations for or against a particular intervention or process.[2–6] In these settings, clinical guidelines may reduce variation in health care quality and improve equity in health care.

However, the effect of guidelines that advocate shared decision making on physician practice patterns is unknown. Shared decision making is the process by which physicians and patients share information with each other, take steps to participate in the decision-making process, and agree on a course of action.[7] Prostate cancer–screening guidelines advocate shared decision making. Prostate cancer is the most common cancer in US men, but the utility of screening for prostate cancer with a prostate-specific antigen (PSA) test is controversial.[8] Although there are 2 large randomized clinical trials currently in progress to determine the utility of PSA screening to date,[9,10] it is unknown whether screening reduces mortality from prostate cancer. Therefore, beginning in 1996 and 1997, the guidelines from the American Cancer Society,[11] American College of Physicians,[12] and the US Preventive Services Task Force[13] recommended shared decision about PSA screening (see the appendix).

A previous physician focus group study demonstrated that physicians who routinely screen with a PSA were more likely to report that clinical practice

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DOI: 10.1177/0272989X08315243

guidelines were not a factor in their screening decisions.[14] We hypothesized that physicians who report a strong effect of guidelines on clinical practice are more likely to be variable PSA screeners because PSA screening guidelines call for incorporating patient preferences and values in decision making. As considerable time, effort, and resources are devoted to developing and implementing guidelines, knowing the effect of guidelines that promote shared decision making on physician practice patterns has important implications on future efforts to create and implement guidelines.

METHODS

This study was approved by the Institutional Review Board at the University of Pennsylvania. We used cross-sectional survey data from the 1998–1999 (Round Two) Community Tracking Study (CTS) Physician Survey.[15,16] The CTS Physician Survey is a biannual longitudinal telephone survey of non–federally employed physicians at 60 sites (51 metropolitan US areas and 9 nonmetropolitan US areas) and of a supplemental national sample of physicians conducted by the Center for Studying Health System Change, which is sponsored by the Robert Wood Johnson Foundation. Data for Round Two were collected just after the concept of shared decision making was introduced in the guidelines in 1996 and 1997 in response to the widespread interest in and rapid uptake of PSA screening for prostate cancer.[17]

The aim of the CTS Physician Survey is to track changes in the health care system and the effects of these changes on the delivery of care by physicians. Participants of the CTS Physician Survey are physicians who provide direct care to patients at least 20 h per week in an office-based or hospital practice. It excludes residents and fellows. Details of the survey are available at www.hschange.org/index.cgi?data = 98. The total number of completed interviews for the 1998–1999 survey was 12,280, for a response rate of 60.9%.

The CTS Physician Survey contains information on physician demographics, medical education, specialty, board certification, practice setting, number of years in practice, practice ownership, practice revenue, source of practice revenue, and provision of charity care. In addition, the survey asks about the perceived effect of clinical practice guidelines on practice. The 1998–1999 round of the CTS Physician Survey also measured PSA screening practice style using a case vignette.

Selection of Study Subjects

Of the 12,280 total responders in the 1998–1999 CTS Physician Survey, 7556 were primary care physicians. For this study, we excluded primary care physicians practicing pediatrics, obstetrics and gynecology, and subspecialties ($n = 3642$) because they are less likely to provide care for the reference patient described in the case vignette: an adult male patient presenting for prostate cancer screening. The final analytic sample consists of 3914 primary care physicians in family practice, internal medicine, and general practice.

Data Collection

Data for the 60 sites were collected by the Center for Studying Health System Change using stratified random sampling with probability proportional to population size. The supplemental sample was selected with stratified random sampling and was included to increase the precision of the national estimates. The sample frame was developed by combining lists of physicians from the American Medical Association and the American Osteopathic Association. Primary care physicians were oversampled in the site sample. The CTS Physician Survey was conducted using a telephone interview. Use of the data was made available through a restricted data use agreement between the principal investigator and the Inter-university Consortium for Political and Social Research at the University of Michigan.

Dependent Variable

The dependent variable is the physician responses to the PSA screening case vignette, which reads as follows:

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> What about PSA (Prostate-specific Antigen) screening in an asymptomatic 60 year old white man who has no family history of prostate cancer and a normal digital rectal exam? For what percentage of such patients would you recommend a PSA test? Consider all your patients with similar clinical descriptions.

Responses ranged from 0% to 100%. Responses were collapsed to create 3 categories: consistent screeners, consistent nonscreeners, and variable screeners, to represent those who would screen all (100%), none (0%), and some (1%–99%) of the patients represented in the case vignette, respectively. Each of these 3 variables were dichotomized to compare the level to all other physicians, thereby creating three 0/1 variables.

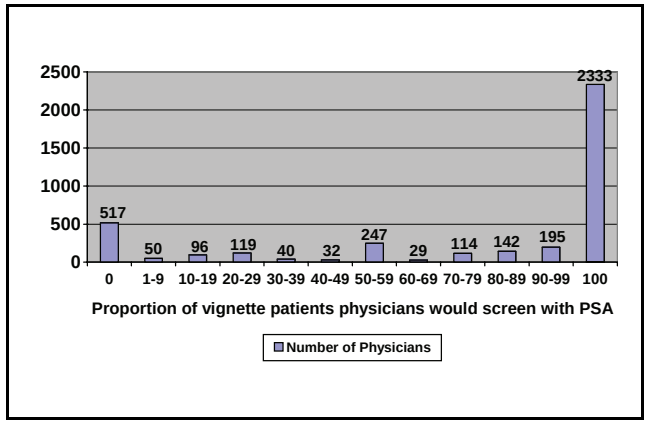

Figure 1 Distribution of physician responses to case vignette.

Independent Variables

The independent variable in this study is the physicians' perceived effect of guidelines on their practice derived from the following question:

> How large an effect does your use of formal, written practice guidelines such as those generated by physician organizations, insurance companies or HMOs [health maintenance organizations] or government agencies, have on your practice of medicine?

Each response was based on a 6-point scale with anchors at *no effect* and *very large effect*. For this analysis, we dichotomized the independent variable into no effect (reference) versus any magnitude effect.

Covariates

The multivariate models adjust for physician age; gender; race; Latino ethnicity; practice specialty; board certification status; foreign medical graduate status; practice setting; number of years in practice; salaried status; income in 1997; Medicare, Medicaid, and managed care as a source of practice revenue; and provision of any charity care.

Statistical Analysis

All statistical analyses were conducted using Stata/SE version 8.2.[18] Descriptive statistics were used to examine the demographic and practice characteristics of consistent screeners, consistent nonscreeners, and variable screeners and their responses to the case vignette. An unadjusted and a multivariate logistic regression model were estimated for each of the 3 groups of physicians, consistent screeners, consistent nonscreeners, and variable screeners, that compared the perceived effect of guidelines in each of the screening group to the other 2 screening groups, yielding a total of 6 regression models. Multivariate models adjusted for physician and practice characteristics. All logistic regression models were estimated taking into account the CTS Physician Survey's complex design. Given the fixed sample size for the current study of 3914 primary care physicians who participated in the 1998–1999 CTS Physician Survey and completed the PSA screening vignette, using a 2-sided statistical test, with an α set at .05 and a minimum detectable difference of 10% probability of being a consistent screener among those who declare no effect versus those who declare any effect of guidelines, this study had 93% power.

RESULTS

Figure 1 shows the frequency of physician responses to the case vignette. The majority (60%) of physicians reported they would recommend screening to all asymptomatic 60-year-old white men (consistent screeners), whereas only 13% reported they would not recommend screening to any such patients (consistent nonscreeners). The remaining 27% of physicians reported that they would recommend screening to 1% to 99% of such patients (variable screeners).

Only 319 (8%) of the physicians perceived guidelines to have no effect on practice, whereas the remaining 3591 (92%) physicians perceived at least some effect of the guidelines. Of these, 13% reported a very small, 27% a small, 35% a moderate, 14% a large, and 4% a very large effect of guidelines on practice.

Table 1 presents the physician and practice characteristics of physicians who were classified as consistent nonscreeners, variable screeners, and consistent screeners. *P* values are presented for the relationship between the 3 categories of screeners and the independent variable and are based on the np trend statistic. Compared with the remainder of physicians, physicians who were variable PSA screeners were least likely to be white ($P = 0.003$), most likely to practice internal medicine ($P = 0.05$), and most likely to be solo practioners ($P < 0.0001$).

Table 2 shows the results of unadjusted and multivariate logistic regression models for the association between the perception of any effect of guidelines on practice and PSA screening pattern. After adjustment for demographic and practice characteristics, physicians who were variable PSA screeners were more likely to report any magnitude effect of guidelines on their practice when compared with physicians in the other 2 groups (adjusted odds ratio [AOR] = 1.73; 95% confidence interval [CI] = 1.25−2.38; $P = 0.001$). Given the heterogeneity in the comparison groups, we compared variable screeners to each of the other 2 groups in separate analyses. When variable screeners were compared with consistent screeners only (omitting the consistent nonscreeners), the AOR was 1.83 (95% CI = 1.32−2.54; $P = 0.001$; not shown in the table). A comparison with consistent nonscreeners did not yield statistically significant results (not shown in the table). Table 2 also shows that in multivariate models physicans who consistently screened their patients with a PSA test were significantly less likely to report any magnitude effect of guidelines on their clinical practice when compared with physicians in the other 2 groups (AOR = 0.61; 95% CI = 0.47−0.79; $P < 0.0001$). Physicians who consistently did not screen their patients did not signficantly differ in the reported effect of guidelines when compared with the other 2 groups of physicians (AOR = 1.16; 95% CI = 0.79−1.71; $P = 0.43$).

Table 3 shows the results of the unadjusted and multivariate logistic regression models for the association between being a variable PSA screener (compared with all other physicians) and physician and practice characteristics as well as the perception that guidelines have any effect on practice (v. no effect). In both unadjusted and multivariate models, an income of $200,000 to $299,999, providing any charity care in the previous month, Medicaid as a source of practice revenue, and the perception that guidelines had an effect on practice were directly associated with being a variable screener. In addition, in multivariate models, nonwhite physicians were more likely to be a variable screeners, and Latino physicians were less likely to be variable screeners.

DISCUSSION

One of the 1st clinical practice guidelines to be widely used was created in 1938 by the American Academy of Pediatrics to provide parameters for the immunization of children.[19] Clinical practice guidelines have since become commonplace, and as of 2007, there were 2249 clinical practice guidelines in the National Guideline Clearinghouse, the national repository of evidence-based guidelines.[20] Considerable time, effort, and resources are devoted to developing and implementing guidelines.[21] Thus, knowledge of how physicians perceive and interpret guidelines is important for providing high-quality care. To our knowledge, this one is the 1st study to use nationally representative physician survey data to examine physician PSA screening patterns and their perceived effect of guidelines on clinical practice.

Our research shows several important findings. First, the majority of physicians (60%) reported that they consistently recommend PSA screening to all their asymptomatic 60-year-old patients. This finding is consistent with previous research that has shown that many, if not most, physicians order screening PSAs at least occasionally.[22–34] Thus, it is not surprising that 75% of men older than 50 years in the United States have previously had a PSA test.[35]

Second, although guidelines recommend shared decision making, only 27% of physicians are variable PSA screeners. Thus, the majority of physicians have a consistent screening strategy, indicating that they may be less responsive to patient values and preferences. From this perspective, the message of shared decision making appears to have had only a limited impact on clinical practice. Research on patients supports this inference. In a cross-sectional analysis of data from the 2000 National Health Interview Survey, approximately one third of men reported their physician did not discuss advantages and disadvantages of prostate cancer screening before offering testing.[36] Two additional studies suggest the problem is even more concerning: one fourth of men who have undergone PSA testing were unaware they had been tested.[37,38] These findings add to the concern that a significant proportion of men are not being given the opportunity to make an informed decision about prostate cancer screening and that the prostate cancer screening guideline recommendation of shared decion

Table 1 Characteristics of Primary Care Physicians Who Are Consistent Nonscreeners, Variable Screeners, and Consistent Prostate-Specific Antigen Screeners

Characteristic of Physicians	Consistent Nonscreeners ($n = 517$)	Variable Screeners ($n = 1064$)	Consistent Screeners ($n = 2333$)	*P* Value[a]
Age, $\bar{x}$ (s)	45.2 (9.8)	46.3 (10.4)	48.8 (11.1)	< 0.0001
Male, *n* (%)	351 (67.9)	782 (73.5)	1837 (78.7)	< 0.0001
Race, no. (%)				0.003
White	377 (72.9)	764 (71.8)	1774 (76.0)	
Black	24 (4.6)	54 (5.1)	99 (4.2)	
Asian	79 (15.3)	184 (17.3)	288 (12.3)	
Native	3 (0.5)	3 (0.3)	12 (0.5)	
Other	8 (1.6)	11 (1.0)	28 (1.2)	
Hispanic/Latino ethnicity, *n* (%)	26 (5.0)	48 (4.5)	132 (5.7)	0.30
Specialty, *n* (%)				0.05
Family practice	207 (40.0)	382 (35.9)	828 (35.5)	
Internal medicine	289 (55.9)	635 (59.7)	1378 (59.1)	
General practice	21 (4.6)	47 (4.4)	127 (5.4)	
Board certified, no. (%)	450 (87.6)	863 (81.7)	1844 (79.7)	< 0.0001
Foreign medical graduate, *n* (%)	105 (20.3)	267 (25.1)	553 (23.7)	0.32
Type of practice, *n* (%)				< 0.0001
Solo, 2, or group physician practice	215 (41.6)	611 (67.4)	1481 (63.5)	
Hospital or medical school	48 (9.3)	74 (7.0)	166 (7.1)	
HMO	155 (30.0)	226 (21.2)	395 (16.9)	
Other	99 (19.4)	153 (14.4)	291 (12.5)	
No. of years in practice, $\bar{x}$ (s)	13.1 (10.2)	14.1 (10.2)	17.0 (11.3)	< 0.0001
Salaried, *n* (%) ($n = 2876$)	349 (67.5)	626 (58.8)	1172 (50.2)	0.02
Annual net income in 1997, $\bar{x}$ (s)	123,011 (58,567)	125,561 (58,966)	139,464 (65,631)	< 0.0001
Source of practice revenue, $\bar{x}$ (s)				
Medicare	33.2 (21.4)	35.9 (20.7)	34.9 (21.3)	0.38
Medicaid	15.4 (15.3)	14.9 (15.4)	10.3 (13.5)	< 0.0001
Managed care	51.4 (30.1)	45.1 (27.4)	48.2 (27.6)	0.66
No charity care provided in previous month, *n* (%)	169 (32.7)	280 (26.3)	746 (32.0)	0.28
How large an effect does your use of formal, written practice guidelines such as those generated by physician organizations, insurance companies or HMOs, or government agencies have on your practice of medicine? *n* (%)				
No effect	38 (7.4)	65 (6.1)	216 (9.2)	
Very small effect	55 (10.6)	120 (11.3)	315 (13.5)	
Small effect	112 (21.7)	300 (28.3)	630 (27.0)	
Moderate effect	216 (41.8)	390 (36.8)	757 (32.5)	
Large effect	68 (13.2)	149 (14.0)	324 (13.9)	
Very large effect	28 (5.4)	37 (3.5)	90 (3.9)	

Note: HMO = health maintenance organization. In some cases, percentages do not add up to 100% because of rounding.
a. *P* values are based on np trend.

making is not being implemented. Much research has been conducted on guideline implemenation. A recent literature review of the facilitators of guideline implementation found that among the 70 successful facilitators identified in the literature, 7 categories emerged: 1) data feedback, 2) reminders or checklists, 3) peer review and in-person feedback, 4) direct supervision, 5) in-service or other educational interventions, 6) mandates, and 7) monetary incentives.[39] Multifaceted interventions targeting different barriers to change are likely to be required to effectively change physician PSA screening behavior.[40–43]

Third, although only a small minority (8%) of physicians report that guidelines have no effect on their clinical practice, those physicians are much less likely to be variable PSA screeners. Our findings

Table 2 Association Between the Perception of Any Effect of Guidelines on Practice and Being a Consistent Nonscreener, Variable Screener, and Consistent Screener of Prostate-Specific Antigen

How Large an Effect Does Your Use of Formal, Written Practice Guidelines Such as Those Generated by Physician Organizations, Insurance Companies or HMOs, or Government Agencies Have on Your Practice of Medicine?	Unadjusted Model			Multivariate Model		
	OR	95% CI	*P*-value	OR	95% CI	*P*-value
Consistent Nonscreener ($n = 517$)	1.38	0.94-2.02	0.10	1.16	0.79-1.71	0.43
Variable Screener ($n = 1,061$)	1.76	1.27-2.42	0.001	1.73	1.25-2.38	0.001
Consistent Screener ($n = 2,332$)	0.56	0.42-0.74	0.0001	0.61	0.47-0.79	0.0001

Note: HMO = health maintenance organization; OR = odds ratio; CI = confidence interval. Each model compares physicians with a specific screening pattern against the other 2 groups of physicians. Models are adjusted for physician age; sex; race; Latino ethnicity; specialty; board certification status; foreign graduate status; practice type; number of years in practice; salaried status; income earned in 1997; proportion of Medicare, Medicaid, and managed care as a source of revenue; and charity care provided in the previous month.

are similar to prior focus group research[14] that shows that routine PSA screeners were less likely to be familiar with the guidelines about PSA screening compared with routine nonscreeners. In fact, in that same study, routine screeners were frequently unable to describe the recommendations of any specific organization, were unaware of the controversy about PSA screening, and believed that population-based screening was universally endorsed. In addition, most routine screeners in that study said that clinical guidelines were not a factor in their screening decisions and that, instead, their practices were based on their clinical experience. Less is known about variable screeners, but one hypothesis is that physicians who are variable screeners interpret the current guidelines in a way that recognizes that screening decisions should be individualized. Based on the findings of this study, clinical guidelines that recommend individualized, informed, shared decision making appear to have some impact on clinical practice: Physicians who report guidelines have an effect on clinical practice are more likely to have PSA screening practice patterns consistent with shared decision making.

Fourth, the current research demonstrates that physicians who are consistent PSA screeners differ from those who are consistent nonscreeners and variable screeners in other ways. Compared with all the remainder of physicians, consistent PSA screeners are more likely to be older, male, white, and in practice longer and to have a higher income and are less likely to be board certified, salaried, and have the lowest proportion of Medicaid as a source of revenue. Conversely, consistent PSA nonscreeners had personal and practice characteristics that were the opposite of consistent screeners. It is possible that the demographic profile of the physicians who are routine screeners represents a group of physicians who are paternalistic, whereby patient input is not sought and thus practice variation is reduced. Cooper and others[14] previously demonstrated that consistent screeners and consistent nonscreeners vary in substantive ways. The major factor influencing PSA practice patterns for consistent screeners was professional and personal experience that supported PSA screening and patient expectations to be screened, whereas the major factor influencing consistent nonscreeners was the lack of definitive evidence of the benefit of PSA screening.

Our study has several limitations. First, the question about screening guidelines in the CTS Physician Survey was not specific to PSA screening, and the data did not allow us to evaluate which clinical practice guidelines are responsible for the perceived effect of guidelines on practice, thereby creating the potential for misclassification bias. Physicians receive guidelines from multiple organizations through different media, and they assimilate the contents of these to largely varying degrees depending on the source. In fact, physicians may experience "guideline fatigue" and not adopt a clinical practice guideline at all.[44] A potential solution is to convene a multisociety task force composed of members of all the relevant organizations to design a single, uniform set of clinical practice guidelines about a topic, as was done with the case of colorectal cancer screening.[45] Although design and approval of these guidelines are more time and labor intensive, such guidelines have the potential to be much more widely and consistently implemented.

Second, the literature shows that there may be other important drivers of PSA screening that we did not have data for and thus could not adjust for,

Table 3 Unadjusted and Multivariate Logistic Regression Results for the Association between Variable Screeners and Physician Demographic Characteristics, Practice Characteristics, and Perceived Effect of Guidelines

Characteristic of Physicians Who Are Variable PSA Screeners	Unadjusted Model			Multivariate Model		
	OR	95% CI	*P* Value	OR	95% CI	*P* Value
Age	0.98	0.97–0.99	0.003	0.99	0.94–1.02	0.25
Female	1.28	0.89–1.84	0.18	1.07	0.80–1.42	0.65
Nonwhite race (compared with white)	1.09	1.01–1.18	0.25	1.09	1.02–1.17	0.01
Hispanic (compared with not Hispanic)	0.90	0.68–1.19	0.45	0.72	0.53–0.97	0.03
Specialty						
Family practice (reference)	—	—	—	—	—	—
Internal medicine	0.95	0.79–1.15	0.65	0.91	0.78–1.07	0.25
General practice	0.72	0.40–1.30	0.27	0.84	0.49–1.46	0.54
Board certification	1.05	0.78–1.43	0.73	1.01	0.76–1.33	0.96
Foreign medical graduate	1.12	0.78–1.60	0.64	0.89	0.59–1.34	0.58
Type of practice (%)						
Solo, 2, or group physician practice (reference)	—	—	—	—	—	—
HMO	0.95	0.64–1.40	0.78	1.16	0.77–1.73	0.47
Hospital or medical school	1.18	0.94–1.48	0.14	1.09	0.88–1.35	0.41
Other	1.03	0.83–1.29	0.79	0.87	0.66–1.16	0.35
Number of years in practice	0.98	0.97–0.99	< 0.0001	1.00	0.97–1.04	0.92
Salaried	1.08	0.98–1.19	0.125	1.12	0.98–1.28	0.09
Annual income in 1997						
$0–$99,999 (reference)	—	—	—	—	—	—
$100,000–$199,999	0.75	0.52–1.09	0.14	0.76	0.52–1.12	0.16
$200,000–$299,999	0.49	0.30–0.82	0.007	0.51	0.31–0.85	0.01
≥$300,000	0.69	0.29–1.64	0.39	0.75	0.31–1.83	0.52
Provide any charity care in previous month	1.31	1.08–1.59	0.008	1.23	1.01–1.51	0.04
Source of practice revenue						
% Medicare (*s*)	1.00	1.00–1.01	0.18	1.00	1.00–1.01	0.04
% Medicaid (*s*)	1.02	1.10–1.02	< 0.0001	1.01	1.01–1.02	< 0.0001
% Managed care (*s*)	0.99	0.99–1.00	< 0.0001	0.99	0.99–1.00	< 0.0001
How large an effect does your use of formal, written practice guidelines . . . have on your practice of medicine?						
Any effect versus no effect	1.76	1.27–2.42	0.001	1.73	1.25–2.38	0.001

Note: PSA = prostate-specific antigen; OR = odds ratio; CI = confidence interval; HMO = health maintenance organization. A consistent screener is defined as screening with PSA at least 80% of patients represented by vignette. All *P* values are 2 tailed.

for example, concerns about medical-legal risk.[46] Third, the dependent variable, PSA screening, was measured using a single isolated variable: a case vignette. Although the case vignette allowed us to control for patient factors and isolate the physician factors associated with PSA screening decision making, a broader assessment of a range of clinical scenarios would strengthen our results. However, several studies have supported the validity of case vignettes in measuring actual physician behavior as responses to case vignettes are correlated with actual clinical behavior.[47–50] Fourth, there is the potential for nonresponse bias, given that the response rate for the 1998–1999 CTS Physician Survey was 61%, a response rate that is not unusually low for physician surveys. Finally, the inferences drawn from this cross-sectional study are limited because this study cannot prove causality between the effect of guidelines and the PSA screening behavior of physicians.

Despite these limitations, this is one of the largest studies to examine the relationship between physician attitudes, guidelines, and PSA screening patterns. These results can inform health care policy makers who seek to improve the quality of cancer screening decisions and develop effective clinical guidelines.

ACKNOWLEDGMENT

Dr. Guerra acknowledges the National Cancer Institute (grant K01 CA-097925) and the Robert Wood Johnson Foundation Amos Medical Faculty Development Program (grant 051895) for their grant support as well as the Center for Studying Health System Change for granting the authors the use of the Community Tracking Study Physician Survey restricted data for the analyses described in this article. Dr. Pagán acknowledges the financial support of the Department of Defense (grant W81XWH-06-1-0334).

APPENDIX

Organization	Year	Recommendation from Guidelines
American Cancer Society[11]	1997	"The ACS recommends that both the PSA test and the digital rectal exam be offered annually, beginning at age 50, to men who have a life expectancy of at least 10 years and to younger men who have a high risk. Information should be provided to patients about the risks and benefits of screening."
American College of Physicians[12]	1997	"Rather than screening all men for prostate cancer as a matter of routine, physicians should describe the potential benefits and known harms of screening, diagnosis, and treatment; listen to the patient's concerns; and then individualize the decision to screen."
US Preventive Services Task Force[13]	1996	"Routine screening for prostate cancer with DRE, serum tumor markers (e.g., PSA), or Transrectal Ultrasound is not recommended ("D" recommendation). Patients who request screening should be given objective information about the potential benefits and harms of early detection and treatment."

Note: PSA = prostate-specific antigen; DRE = digital rectal examination.

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J Canc Educ
DOI 10.1007/s13187-011-0239-6

Health Literacy and Breast Cancer Screening among Mexican American Women in South Texas

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Abstract Breast cancer is the main cause of cancer deaths for Hispanic women. This study analyzes the role of functional health literacy on mammography screening behavior and adherence of Hispanic women. Survey data from 722 Mexican American women age 40 and over residing in the Lower Rio Grande Valley of Texas in 2008 were used to estimate logistic regression models to assess the role of functional health literacy on mammography screening behavior and adherence. About 51% of survey respondents had a functional health literacy level deemed as inadequate or marginally functional. After adjusting for other factors, women with adequate health literacy levels were more likely to report to have ever had a mammogram (odds ratio [OR]=2.92; 95% confidence interval [CI]=1.62–5.28), to have had a mammogram within the last 2 years (OR=1.70; 95% CI=1.14–2.53) or to have had one within the last year (OR=2.30; 95% CI=1.54–3.43), compared to women with inadequate or marginally adequate functional health literacy levels. Inadequate/marginal functional health literacy is strongly associated with lower mammography screening. Large improvements in breast cancer control in this population may come from either basic advances in health literacy or by tailored approaches to help women with low literacy navigate local health care systems.

Keywords Mammography · Mexican American · Health literacy

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Introduction

With a mortality rate of 15.6 per 100,000, breast cancer is the primary cause of cancer deaths for Hispanic women. About 55% of the breast cancer cases for Hispanic women are diagnosed at the local stage compared to 63% of breast cancer cases for non-Hispanic white women and tumors are larger at diagnosis for Hispanic women compared to non-Hispanic whites [1]. Lower mammography screening rates and lack of follow up of abnormal screening outcomes seem to be the major factors accounting for these differences in breast cancer stage at diagnosis [2, 3]. Of all ethnic/racial groups, Latina women aged 40 and older have

Published online: 15 May 2011

the lowest 2-year mammography screening rates in the country (59.6% compared to, for example, 68.1% for non-Hispanic whites) [1]. Moreover, Mexican-origin women have lower 2-year mammography screening rates compared to other Latina subgroups (56.2% compared to 57.8%, 72.7%, and 63.9% for Puerto Rican, Cuban, and Central/South American women, respectively) [1].

Achieving appropriate screening rates for breast cancer for the Mexican-origin U.S. population represents a significant opportunity to reduce breast cancer morbidity/mortality for an ethnic group facing many breast cancer screening barriers. Lack of health insurance coverage and income are important barriers to mammography utilization but, nonetheless, screening affordability alone does not explain the limited screening in this population [4].

Health literacy has been defined as "the ability to obtain, process, and understand basic health information and services to make appropriate health decisions" [5]. Low health literacy has been shown to be associated with a limited health vocabulary and it limits how individuals understand the concept of screening and their awareness of its benefits. For example, participants in focus groups and individual interviews in several studies thought screening was unnecessary if their breasts "looked good" or if they had no symptoms [6]. Compared with women with marginal and adequate literacy, women with low literacy were significantly more likely to have negative attitudes about mammography including that a mammogram would be embarrassing, harmful, or painful, and were also more likely to feel that it would be a lot of trouble to get a mammogram [6]. Limited health literacy also reduces patients' understanding of both oral and written information related to breast cancer screening recommendations and processes, in particular written materials because the average readability level of the available cancer screening literature has been found to be in the 10th–11th grade reading level [7, 8]. Furthermore, low literacy hinders navigation through a complex health care system, limits an individual's ability to complete health forms, understand appointment slips, interpret medication instructions accurately, and effectively communicate with their physician [9]. Patients with low or poor health literacy may lack numeracy skills to understand and assess the risks and benefits of mammography screening than patients with better health literacy [10].

Survey data from the 2003 National Assessment of Adult Literacy (NAAL)—the most recent data available—show that only 12% of the U.S. adult population has a health literacy level deemed as proficient, and more than a third (77 million people) have a health literacy level classified as basic or below basic [5]. These adults would have difficulty with tasks such as reading a health pamphlet and explaining why someone should not undergo a test for a health condition/disease, or with understanding the directions in a prescription drug label. Moreover, health literacy varies substantially across racial/ethnic groups and health insurance coverage status. About 65% of Hispanic adults have a basic or below basic health literacy level compared to 57% of non-Hispanic blacks and 28% of non-Hispanic whites [5]. About 53% of uninsured adults have a basic or below basic health literacy level compared to 24% of adults with employer-provided health insurance coverage [5].

We examined the association between functional health literacy and mammography screening behavior and adherence among Hispanic women residing in the Lower Rio Grande Valley of Texas, one of the poorest regions in the United States, which also is characterized by high uninsurance rates and very low mammography screening rates [4, 11]. Previous studies assessing the role of functional health literacy on mammography screening behavior of Latinas have shown that functional health literacy is related to ever having a mammogram but it is not related to key measures related to adherence such as having a mammogram within the last 1 or 2 years [12]. Studies which have identified health insurance coverage as the main determinant of breast cancer screening for Latina populations did not explicitly account for functional health literacy as a key factor in breast cancer screening behavior [4]. As such, the primary hypothesis of this study is that inadequate health literacy is independently associated with low mammography uptake and adherence, even after accounting for health insurance coverage status, household income, and other demographic and socioeconomic factors.

Methods

We interviewed 736 Mexican American women selected at random from a population-based panel study of middle-aged and older Latinos/as residing in the Rio Grande Valley of South Texas (the Border Epidemiologic Study on Aging, BESA). The BESA sample was first interviewed in 1994–1996 (1,089) and participants were selected at random from the Latino population in the Rio Grande Valley. This region of South Texas includes the counties of Cameron, Hidalgo, and Starr. The original BESA sample was augmented through additional data collection waves conducted from 1998 to 2006 [13].

The mammography screening module included responses from a random sample of Latinas 40 years of age and older. Face-to-face interviews were conducted in either English or Spanish from January to June 2008. Written informed consent was obtained before interviewing study participants at their home. Survey participants were compensated with a $30 gift card from a local supermarket

and interviews were 20 to 30 min long. The study protocol was approved by the institutional review boards of the University of Texas-Pan American and the University of North Texas Health Science Center, and reviewed by the U.S. Army Medical Research and Materiel Command's Office of Research Protections, Human Research Protection Office.

Study respondents provided demographic and socioeconomic information as well as answers to questions related to their knowledge, attitudes, and behaviors about breast cancer and mammography screening. More specifically, all survey participants were asked a general yes/no question "Have you ever had a mammogram?" Respondents who answered "yes" were then asked "When did you have your last mammogram?" and categorical responses to this question ("Within 1 year," "Between 1 and 2 years," "Between 2 and 3 years," "Between 3 and 5 years," and "More than 5 years") were recoded to create two adherence variables: whether or not the respondent reported a mammogram within the last year and whether or not the respondent had reported a mammogram within the last 2 years. Respondents with "Don't know" and "No Answer" responses were excluded from the analysis.

Survey participants were also given the Short Test of Functional Health Literacy (STOFHLA) in either English or Spanish [14]. The STOFHLA includes two reading comprehension passages—patient medical instructions for preparing for an X-ray and the rights and responsibilities section of a Medicaid application form. The test includes 36 questions and both the English and Spanish versions of the survey instrument have been validated [15]. Respondents with a STOFHLA score of 23–36 were classified as having adequate functional health literacy while respondents with scores ranging from 0 to 16 and from 17 to 22 were classified as having inadequate and marginal functional health literacy, respectively [14].

There are other relevant variables which are likely to be related to mammography screening behavior and adherence. These variables include age (40–49, 50–59, 60–69, and 70 and above years of age), educational attainment (less than high school, high school and some college education or college graduate), marital status (married and not married), household income (more than $10,000 and less than $10,000 per year), health insurance coverage (insured and uninsured) and U.S. acculturation level. Acculturation was measured with the Short Acculturation Scale for Hispanics (SASH), a 12-question instrument reflecting language use, media and ethnic social relations [16–18]. Each question is scored from 1 to 5 points. Higher acculturation is defined as having a SASH average score of three points or higher.

Multiple imputation of missing responses was performed using multivariate normal regression in Stata/MP 11.1 [19]. Variables with imputed values included years of education (n=1), acculturation (n=7), and household income (n=80). An iterative Markov chain Monte Carlo (MCMC) method—using a multivariate normal model and conducting five imputations—was used to impute these missing values [20]. The analyses also were conducted based on excluding missing values using casewise deletion but the results of the study did not change in any meaningful way.

Results

Table 1 describes the sample of 722 respondents used in the analysis. Almost 86% of respondents reported that they ever had a mammogram done. About 62% said that they had a mammogram within the last 2 years and 44% stated that they had a mammogram within the last year. More than half the respondents were over 60 years of age. Almost

Table 1 Characteristics of respondents

Characteristics	%
Mammography screening	
Ever had a mammogram	85.46
Had a mammogram within the last 2 years	62.05
Had a mammogram within the last year	44.32
Age	
40–49 years	17.31
50–59 years	23.55
60–69 years	24.79
70+ years	34.35
Educational Attainment	
Less than high school	69.79
High school	15.94
Some college education or college graduate	14.27
Marital Status	
Married	57.48
Not married	42.52
Household Income	
More than $10,000 per year	41.74
Less than or equal to $10,000 per year	58.26
Health insurance coverage	
Insured	73.27
Uninsured	26.73
U.S. acculturation level	
Lower (SASH score below 3)	79.47
Higher (SASH score equal to or above 3)	20.53
Functional Health Literacy	
Adequate (STOFHLA score above 22)	49.58
Inadequate/marginal (STOFHLA score below 23)	50.42
N	722

70% of respondents had less than a high school education. About 58% of respondents were married and 58% had a household income of less than $10,000 a year. A quarter of respondents (27%) had no health insurance coverage and four out of every five respondents (79%) had SASH scores consistent with a relatively low level of U.S. acculturation. Half of all survey participants had inadequate or marginal functional health literacy (STOFHLA) scores (50%).

Table 2 reports the results of logistic regression models for ever having mammography screening, having a mammogram within the last 2 years and having a mammogram within the last year. Unadjusted and adjusted results are reported for all the three mammography screening variables. Unadjusted results only included the variable being considered in the estimated logistic regression model (e.g., only years of age categories were included in the unadjusted odds ratios (OR) reported for the age indicator variables) while adjusted results included all the variables in each estimated logistic regression model.

In adjusted regression models, respondents ages 50–69 had higher odds of ever having a mammogram compared to all other respondents (OR=2.23; 95% confidence interval [CI]=1.10–4.51) and (OR=2.36; 95% CI=1.11–5.03) while respondents 60–69 had lower odds of having a mammogram within the last year compared to all other respondents (OR=0.49; 95% CI=0.29–0.84). Educational attainment and marital status were not significantly related to mammography screening behavior and adherence in adjusted regression models. Although high household income was associated with mammography screening behavior and adherence, the ORs become statistically insignificant after adjusting for all the other demographic and socioeconomic variables included in the models. The same result applies to U.S. acculturation level—low acculturation was related to low mammography screening propensity but only in unadjusted logistic regression models. Health insurance coverage was consistently related to the three mammography screening indicators in both unadjusted and adjusted logistic regression models (with uninsured respondents much less likely to ever had a mammogram or to have had a mammogram within the last 1 or 2 years, than insured respondents).

Adequate functional health literacy was strongly and consistently associated with higher mammography screening uptake and adherence in both unadjusted and adjusted logistic regression models. In adjusted models, those with STOFHLA scores above 22 were more likely to report that they ever had a mammogram (OR=2.92; 95% CI=1.62–5.28), had a mammogram within the last 2 years (OR=1.70; 95% CI=1.14–2.53) and had a mammogram within the last year (OR=2.30; 95% CI=1.54–3.43).

Table 2 Logistic regression results: mammography screening

	Ever had a mammogram		Had a Mammogram within the last 2 years		Had a mammogram within the last year	
	Unadjusted odds ratio [95% CI]	Adjusted odds ratio [95% CI]	Unadjusted odds ratio [95% CI]	Adjusted odds ratio [95% CI]	Unadjusted odds ratio [95% CI]	Adjusted odds ratio [95% CI]
Age: 50–59 years	1.60 [0.83–3.09]	2.23* [1.10–4.51]	1.24 [0.75–2.05]	1.44 [0.85–2.44]	0.80 [0.50–1.27]	0.88 [0.54–1.44]
Age: 60–69 years	1.38 [0.73–2.59]	2.36* [1.11–5.03]	0.71 [0.44–1.14]	0.82 [0.48–1.42]	0.43** [0.27–0.69]	0.49** [0.29–0.84]
Age: 70+ years	1.14 [0.65–2.03]	2.26 [0.98–5.22]	0.59* [0.38–0.93]	0.68 [0.37–1.25]	0.49** [0.32–0.76]	0.59 [0.33–1.1]
Educational Attainment: Less than high school	0.44* [0.20–0.93]	0.83 [0.33–2.08]	0.39** [0.24–0.64]	0.61 [0.33–1.12]	0.51** [0.33–0.78]	0.93 [0.53–1.60]
Educational Attainment: High school	0.63 [0.25–1.56]	0.72 [0.28–1.87]	0.79 [0.42–1.5]	0.83 [0.44–1.59]	1.09 [0.63–1.9]	1.20 [0.68–2.11]
Marital Status: Married	1.27 [0.84–1.93]	1.11 [0.67–1.83]	1.35 [1.00–1.83]	1.13 [0.78–1.64]	1.45* [1.07–1.96]	1.20 [0.83–1.71]
Household Income: Less than or equal to $10,000 per year	1.77** [1.17–2.70]	1.37 [0.81–2.31]	1.59** [1.16–2.17]	1.01 [0.68–1.50]	1.71** [1.26–2.31]	1.10 [0.74–1.62]
Health Insurance Coverage: Uninsured	0.56* [0.36–0.87]	0.54* [0.30–0.94]	0.65* [0.46–0.90]	0.44** [0.29–0.68]	0.62** [0.44–0.87]	0.38** [0.25–0.60]
U.S. Acculturation Level: Lower (SASH score below 3)	0.50* [0.27–0.93]	0.92 [0.43–1.99]	0.56** [0.38–0.84]	1.28 [0.76–2.14]	0.65* [0.46–0.94]	1.54 [0.95–2.50]
Functional Health Literacy: Adequate (STOFHLA score above 22)	2.31** [1.49–3.56]	2.92** [1.62–5.28]	2.14** [1.57–2.91]	1.70** [1.14–2.53]	2.51** [1.86–3.40]	2.30** [1.54–3.43]

*$p<.05$, ** $p<.01$

Discussion

In 2010, an estimated 207,090 women in the United States were diagnosed with breast cancer and 39,840 would die from it [21]. Breast cancer is the most commonly diagnosed cancer among Latinas and substantial breast cancer screening disparities exist across Latina subgroups. Mammography screening rates for Latinas in the South Texas border region are very low, with only 44% of respondents in our study reporting that they had a mammogram within the last year.

Accurate identification of screening barriers is a fundamental step required before interventions to increase mammography utilization among Latinas can be designed and implemented effectively. Considerable attention has been focused on barriers within the health care system—such as inadequate health insurance coverage. And while system-level internal barriers are real and important, more fundamental population factors may have larger effects. We have identified inadequate functional health literacy as an important factor related to mammography uptake and adherence in our study population. One of every two of our Mexican-origin Latina respondents surveyed had STOFHLA scores which place them in the category of having marginal or inadequate health literacy skills. And more than any other factor measured in this study, low health literacy was strongly associated with lower mammography uptake.

Even though the causal directions, pathways, and mechanisms of these strong associations are not established by this study, low literacy is such a foundational deficit that it is likely to be at least partly mediating our observations—even if it is partly codetermined by other, more fundamental factors. While we await later studies that might untangle these effects, our results offer some plausible strategies to improving Latina breast cancer screening. Therefore, while increasing health insurance coverage in the South Texas border region will probably increase mammography screening rates in this region of the country substantially, improving health literacy levels may have a larger effect, and one that may sustain welfare benefits beyond health. And while improving literacy is challenging, we can, in the meantime, recognize that health information needs to be provided in ways that are easily understood by everyone.

For example, designing print health materials at appropriate reading levels is necessary to make them accessible to larger segments of the population, but they also need to be continuously redesigned and tested to better match the needs of the intended audience [5]. This is particularly relevant in U.S.–Mexico border communities, which are characterized by rapidly changing population patterns related to immigration. Another promising approach to address health literacy challenges related to breast cancer screening is to use patient navigators (community health workers or promotoras) as this workforce is already embedded in many border communities and they can readily assist low literacy populations in obtaining breast cancer information. Recent studies have shown that the use of community health workers can increase mammography screening and self-efficacy as well as the level of perceived susceptibility and benefits of breast cancer screening in U.S.–Mexico border communities [22, 23]. Thus, community health workers not only can help to improve health literacy levels by delivering educational materials but they can also help low literacy populations to effectively access health care services available in local communities.

South Texas border communities have the highest rates of uninsurance in the United States and these local health care markets will see disproportionate increases in health insurance coverage rates as a result of the recent health care reform efforts. The development of tailored mammography screening materials and health care system navigating processes for these populations offer a promising opportunity to better meet their needs, particularly of women of screening age which will be participating in new health public and private health insurance coverage programs in this region.

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Appendix B

Survey Instrument

Participant No: _____ Date: _____ Interviewer: _____

Section 1. Demographics

1. Age: ____

2. Sex: ❒ Male ❒ Female

3. Marital Status: ❒ Married ❒ Single, never married ❒ Divorced ❒ Separated ❒ Widowed

4. Where were you born? ❒ United States **[Go to 6]** ❒ Mexico ❒ Other_____

5. In which year did you come to live in the United States? Year: _____

6. What is the highest grade or year of school you completed?
   - ❒ Never attended school or only attended kindergarten
   - ❒ Grades 1 through 8 (Elementary)
   - ❒ Grades 9 through 11 (Some high school)
   - ❒ Grade 12 or GED (High school graduate)
   - ❒ College 1 year to 3 years (Some college or technical school)
   - ❒ College 4 years or more (College graduate)

7. Are you currently…?
   - ❒ Employed full time
   - ❒ Employed part time
   - ❒ Retired **(Go to 9)**
   - ❒ Disabled **(Go to 9)**
   - ❒ Unemployed and looking for work **(Go to 9)**
   - ❒ Have never worked **(Go to 9)**
   - ❒ Other (specify) _____ **(Go to 9)**

8. On average, how many hours per week do you work at your main job? _____

9. Occupation: _____

10. What do you estimate your total household income is per month from all sources?
    $_____ x 12 = $_____
    (Month) (Year)

Section 2. Health Status and Health Care Use

1. Would you say that in general your health is:
   - ❒ Excellent
   - ❒ Very good
   - ❒ Good
   - ❒ Fair
   - ❒ Poor

2. Compared to 5 years ago, do you think that your physical health is…
   ❒ Better ❒ About the same ❒ Worse ❒ No Answer

3. Compared to last year, do you think that your physical health is…
   ❒ Better ❒ About the same ❒ Worse ❒ No Answer

4. Have you been diagnosed by a medical doctor with any of the following conditions or illnesses?
   - ❒ Hardening of the arteries
   - ❒ High blood pressure

❒ Heart trouble: angina, heart attacks, and arrhythmia
❒ Effects of stroke
❒ Cancer
❒ Nerve or muscle problems such as neuralgia, Parkinson's disease, or seizures
❒ Forget things often
❒ Gastric ulcers, problems with colitis, hemorrhoids
❒ Problems with joints or bones
❒ Gallbladder
❒ Kidney or urinary problems (hemodialysis)
❒ Liver problems
❒ Respiratory problems, emphysema, asthma, bronchitis
❒ Skin problems, rashes, bed sores, eczema, sores and ulcers
❒ Diabetes
❒ Neurosis/Anxiety/Depression

5. Do you have a regular doctor that you go to when you get sick? ❒ Yes ❒ No

6. If the answer is "Yes", is the doctor in…? ❒ United States ❒ Mexico ❒ Other

7. Have you received any type of medical attention in Mexico? ❒ Yes ❒ No
If the answer is "Yes", was it from… (check all that apply)
❒Pharmacist
❒Hospital
❒Dentist
❒Doctor
❒Other (specify) _____

8. Have you had a Pap smear? ❒ Yes ❒ No
If yes, how long ago?
❒ Within the last year
❒ Within the last 5 years
❒ More than 5 years ago
❒ Don't Know
❒ No Answer

9. Do you have…? (Check all that apply)
❒ Medicare-Part A (Hospital)
❒ Medicare-Part B (Doctor)
❒ Medicaid
❒ Private Health Insurance
❒ Veterans
❒ Other
❒ Uninsured

10. How many times you have been in the hospital during this last year? _____

11. How many times you have been to the doctor during this last year? _____

Section 3. Breast Examination

1. Have you heard of a mammogram? ❒ Yes ❒ No **(Go to 3)** ❒ Don't know ❒ No Answer

2. Where did you learn about mammograms?
❒ Television
❒ Health fair
❒ Personal doctor
❒ Nurse
❒ Friend
❒ Other (specify) _____
❒ Don't know

3. Do you know what a mammogram is? ❒ Yes ❒ No ❒ Don't know ❒ No Answer

4. Why are women given mammograms? (Write a verbatim response)
_____
_____

5. Have you ever had a mammogram? ❒ Yes ❒ No **(Go to 14)** ❒ Don't know ❒ No Answer

6. Was it part of a check up, breast problem or both? ❒ Check up ❒ Breast problem ❒ Both
❒ Don't know ❒ No answer

7. When did you have your last mammogram?
❒ Within 1 year
❒ Between 1 and 2 years
❒ Between 2 and 3 years
❒ Between 3 and 5 years
❒ More than 5 years
❒ Don't know

8. Where did you go for your mammogram? (Specify)_____

9. In what country did you have your last mammogram?
❒ U.S. ❒ Mexico ❒ Other (specify) _____

10. How were you told the results of the mammogram?
❒ In person
❒ By telephone
❒ Through the mail
❒ Combination of methods
❒ Never told, which means results were normal
❒ Never told; if problem

11. In what language were you told the results?
❒ Spanish ❒ English ❒ Both ❒ Other (specify) _____

12. Were you able to understand these results?
❒ Yes **(Go to 14)** ❒ No ❒ Don't know ❒ No Answer

13. What was the reason?
❒ Difficulty understanding the language
❒ Did not understand what the results meant
❒ I cannot read (if results received by mail/in writing)
❒ Other (specify)_____

14. Would you know where to go for a mammogram now? ❒ Yes ❒ No ❒ Don't know ❒ No Answer
a. If yes, where? Specify_____

15. If patient has not had a mammogram or has not had a mammogram in the last year, what is the most important reason why? (If necessary, probe: "And what was the most important reason?" and read list.)
_____
_____
❒ Put it off
❒ Didn't know I should
❒ Not needed/Not necessary
❒ Costs too much
❒ No insurance coverage
❒ Don't go to doctors
❒ Don't have a personal doctor
❒ Not recommended by doctor
❒ Doctor said it wasn't needed
❒ Too embarrassing

- ❒ Haven't had any problems
- ❒ Fear
- ❒ Fear of radiation
- ❒ Painful procedure
- ❒ Unpredictable results
- ❒ Not able to communicate with doctor because of language differences
- ❒ Other (specify) _____
- ❒ Don't know

16. Did anyone ever say that you should have a mammogram? ❒ Yes ❒ No ❒ Don't know ❒ No Answer

a. If yes: Who said you should have a mammogram?

- ❒ Doctor
- ❒ Husband
- ❒ Family
- ❒ Friend
- ❒ Other (specify)_____

17. How old do you think a woman should be before she begins having mammograms?

- ❒ Less than 40
- ❒ Between 40 and 49
- ❒ Between 50 and 59
- ❒ Over 60
- ❒ Don't know

18. How often do you think a woman should have a mammogram after she reaches that age?

- ❒ More than one time a year
- ❒ One time each year
- ❒ One time every 2 years
- ❒ One time every 3 years
- ❒ One time every 4 years
- ❒ One time every 5 years or more
- ❒ Don't know
- ❒ Other (specify) _____

19. Do you check your breasts for lumps? ❒ Yes ❒ No ❒ Don't know ❒ No Answer

a. If yes: About how often?

- ❒ Once a week
- ❒ Two or more times each week
- ❒ Once each month
- ❒ Two or more times each month
- ❒ 2-4 times each year
- ❒ 5-8 times each year
- ❒ 8-12 times each year
- ❒ Never
- ❒ Other (Specify) _____
- ❒ Don't know

20. With respect to a woman's period, when do you think a woman should check her breasts for lumps?

- ❒ Before
- ❒ During
- ❒ After
- ❒ This does not apply to me; I do not get my period anymore/I am pregnant
- ❒ Other (specify) _____
- ❒ Don't know

21. In your opinion, how effective is mammography at finding cancer early?

- ❒ Not effective at all
- ❒ Not very effective
- ❒ A little effective
- ❒ Very effective

❒ Don't know

22. If you find breast cancer early, what are the chances it can be cured?
❒ Very Poor
❒ Poor
❒ OK
❒ Good
❒ Very Good
❒ Don't know

23. If you find breast cancer late, what are the chances it can be cured?
❒ Very Poor
❒ Poor
❒ OK
❒ Good
❒ Very Good
❒ Don't know

24. If a doctor recommended a mammogram as a routine check-up, how likely would you be to get one?
❒ Not at all
❒ Probably Not
❒ Maybe
❒ Probably Yes
❒ For sure

25. If a doctor told you that you might have cancer, how likely would you be to get a mammogram?
❒ Not at all
❒ Probably Not
❒ Maybe
❒ Probably Yes
❒ For sure

26. If a friend recommended a mammogram, how likely would you be to get one?
❒ Not at all
❒ Probably Not
❒ Maybe
❒ Probably Yes
❒ For sure

27. If a relative recommended a mammogram, how likely would you be to get one?
❒ Not at all
❒ Probably Not
❒ Maybe
❒ Probably Yes
❒ For sure

28. How concerned are you that a mammogram will be embarrassing?
❒ Extremely concerned
❒ Very concerned
❒ Somewhat concerned
❒ A little concerned
❒ Not at all concerned

29. How concerned are you about a mammogram being harmful?
❒ Extremely concerned
❒ Very concerned
❒ Somewhat concerned
❒ A little concerned
❒ Not at all concerned

30. How concerned are you about a mammogram being painful?

❒ Extremely concerned
❒ Very concerned
❒ Somewhat concerned
❒ A little concerned
❒ Not at all concerned

31. How concerned are you about the cost of a mammogram?
❒ Extremely concerned
❒ Very concerned
❒ Somewhat concerned
❒ A little concerned
❒ Not at all concerned

32. Has a doctor ever told you that you had cancer of any kind? ❒ Yes ❒ No ❒ Don't know ❒ No Answer

a. If yes: What kind of cancer was it?_____

33. Has anyone in your family had cancer of any kind? ❒ Yes ❒ No ❒ Don't know ❒ No Answer

a. If yes: Who? _____
b. What type of cancer was it? _____

34. What do you think your chances of getting breast cancer are?
❒ Not at all
❒ Probably Not
❒ Maybe
❒ Probably Yes
❒ For sure
❒ Don't know

35. Do you know anyone who has had breast cancer? ❒ Yes ❒ No ❒ Don't know ❒ No Answer

a. If yes: Who? _____

36. How concerned are you that you will find out you have cancer if you have a mammogram?
❒ Extremely concerned
❒ Very concerned
❒ Somewhat concerned
❒ A little concerned
❒ Not at all concerned

37. How much trouble do you think it will be for you to get a mammogram?
❒ Too much trouble
❒ A lot of trouble
❒ A little trouble
❒ Hardly any trouble
❒ No trouble at all

38. Have you wanted information to help you make a decision about mammography?
❒ Yes ❒ No ❒ Don't know ❒ No Answer

39. If you have cancer, do you want to know it? ❒ Yes ❒ No ❒ Don't know ❒ No Answer

40. When do you think it is especially important to get a mammogram?

a. When there is breast cancer in your family: ❒ Yes ❒ No ❒ Don't know ❒ No Answer

b. When there is no breast cancer in your family: ❒ Yes ❒ No ❒ Don't know ❒ No Answer

c. Whether or not there is breast cancer in your family: ❒ Yes ❒ No ❒ Don't know ❒ No Answer

Section 4. Acculturation

	Only Spanish	Spanish better than English	Both Equally	English better than Spanish	Only English
In general, what language(s) do you read and speak?	1	2	3	4	5
	Only Spanish	More Spanish than Eng.	Both Equally	More English than Span.	Only English
What language(s) did you speak as a child?	1	2	3	4	5
What language(s) do you usually speak at home?	1	2	3	4	5
In which language(s) do you usually think?	1	2	3	4	5
What language(s) do you usually speak with your friends?	1	2	3	4	5
In what language(s) are the TV programs you usually watch?	1	2	3	4	5
In what language(s) are the radio programs you usually listen to?	1	2	3	4	5
In general, in what language(s) are the movies, TV, and radio programs you prefer to watch and listen to?	1	2	3	4	5
	All Latinos/ Hispanics	More Hispanics/ Latinos than Americans	About Half and Half	More Americans than Hispanics/ Latinos	All Americans
Your close friends are:	1	2	3	4	5
You prefer going to social gatherings/parties at which the people are:	1	2	3	4	5
The people you visit or who visit you are:	1	2	3	4	5
If you could choose your children's friends, you would want them to be:	1	2	3	4	5

Section 5. Health Care System Distrust

The next questions are about your opinion of the health care system in general. When we refer to the health care system, we mean hospitals, health insurance companies, and medical research. For each statement below, please check how strongly you agree or disagree.

a. Medical experiments can be done on me without my knowing about it.
❒ Strongly Agree ❒ Agree ❒ Not Sure ❒ Disagree ❒ Strongly Disagree

b. My medical records are kept private.
❒ Strongly Agree ❒ Agree ❒ Not Sure ❒ Disagree ❒ Strongly Disagree

c. People die every day because of mistakes by the health care system.
❒ Strongly Agree ❒ Agree ❒ Not Sure ❒ Disagree ❒ Strongly Disagree

d. When they take my blood, they do tests they don't tell me about.
❒ Strongly Agree ❒ Agree ❒ Not Sure ❒ Disagree ❒ Strongly Disagree

e. If a mistake were made in my health care, the health care system would try to hide it from me.
❒ Strongly Agree ❒ Agree ❒ Not Sure ❒ Disagree ❒ Strongly Disagree

f. People can get access to my medical records without my approval.
❒ Strongly Agree ❒ Agree ❒ Not Sure ❒ Disagree ❒ Strongly Disagree

g. The health care system cares more about holding costs down than it does about doing what is needed for my health.
❒ Strongly Agree ❒ Agree ❒ Not Sure ❒ Disagree ❒ Strongly Disagree

h. I receive high-quality medical care from the health care system.
❒ Strongly Agree ❒ Agree ❒ Not Sure ❒ Disagree ❒ Strongly Disagree

i. The health care system puts my medical needs above all other considerations when treating my medical problems.
❒ Strongly Agree ❒ Agree ❒ Not Sure ❒ Disagree ❒ Strongly Disagree

j. Some medicines have things in them that they don't tell you about.
❒ Strongly Agree ❒ Agree ❒ Not Sure ❒ Disagree ❒ Strongly Disagree

Appendix C

Abstracts of Studies in Call for Proposals by the South Texas Border Health Disparities Center

Proposal 1: Recommended for funding.
Title: Addressing healthcare disparities through the development of affordable anticancer therapeutics.
PIs:
Joanne Rampersad- Project Director-University of Texas- Pan American
David Ammons- Senior Collaborator- University of Texas- Pan American
John Short- Senior Collaborator- University of Texas Health Science Center San Antonio Edinburg Regional Academic Health Center
George Fox- Senior Collaborator- University of Houston
Janet Siefert- Senior Collaborator- Rice University

Abstract
Finding effective treatments for cancer are at the forefront of ongoing biomedical research. Aside from being a serious life-threatening disease, cancer can place an overwhelming financial and emotional burden on patients and their families, especially among the poor. Thus effective treatments are required that fight cancers, while being affordable to all. Nowhere is this truer than along the U.S. border region with Mexico, a region characterized by both poverty and healthcare disparities. Evidence is emerging that protein toxins (called Parasporins) from the bacterium *Bacillus thuringiensis* (Bt), used globally in agriculture to control insects, are also effective against human cancer cells. This exciting finding is opening a new, and potentially transforming, front in the fight against cancer. To date, researchers have identified 6 different types of parasporins that are effective against different types of cancers, and new and more effective parasporins are being sought. The Applicant, as a long-time researcher in Bt toxins, has an existing library of over 650 Bt strains. An initial screen of 200 of these isolates has resulted in the discovery of two anti-cancer parasporin toxins, along with several other strains with toxins that need further characterization. This proposal seeks funding to screen and characterize the rest of the Applicants approximately 450 Bt strains for anticancer activity. Anti-cancer screening will be performed in collaboration with Dr. John Short, a research scientist at the UTHSCSA-Regional Academic Health Center (located adjacent to the UTPA campus). The screen is expected to identify additional toxins with homology to the known family of 6 parasporin types. In addition, based on results of the Applicant's initial screen of 200 isolates, it is further expected that novel anti-cancer toxins will also be identified. With the physical toxins in hand, future research will be directed at understanding mechanisms of action, modifying the toxin's structure to enhance its potency and specificity, and exploring novel, affordable approaches for their use in controlling human cancers. In context to the phenomenal success of Bt toxins in agriculture, our ultimate goal is to provide an inexpensive and effective tool in the fight against cancer, which is accessible to all.

Proposal 2: Not recommended for funding

Title: Correlates of Preventive Screening and Healthcare Utilization for Breast Cancer and Diabetes Among US-Mexico Border Hispanics

PI: Xiaohui Wang, University of Texas-Pan American

Abstract
Death from breast cancer is often preventable. Limited access to health care is one of the barriers in explaining Latinas (breast) cancer disparities. Health experts agree that mammography and breast self-exams are two of the best ways to detect breast cancer early. Research showed that regardless of insured status African American and Hispanic women experienced greater delays (measured by the number of days from abnormal screening to definitive diagnosis) in diagnosing breast cancer than Caucasian women. Studies showed, however, that Latinas often fail to take advantage of such preventative measures. The burden of diabetes is especially alarming in U.S.-Mexico border communities, a region with a predominantly Hispanic population. Diabetes is a costly disease. The American Diabetes Association highlights that the diabetes related economic and social burden affects not only individuals and their families, but all society by facing higher insurance premiums and taxes and a reduced standard of living. Although it is well documented that prevention care practices and regular care are effective in reducing or delaying the onset of diabetes complications, diabetes-related ethnic disparities in healthcare access are pervasive. It is important to find out what are the barriers to preventive screening and healthcare access to US-Mexico border Hispanic population. In addition, reality of cancer disparities calls for identification of barriers for Latinas to understand that cancer is preventable, and treatable if caught in time, which starts with a screening. Once these barriers are identified, culturally appropriate interventions can be developed to help the disadvantage target population. Our research goal is to determine the level of preventive screening and healthcare access among US-Mexico border Hispanics; and to identify correlates to several specific types (breast cancer screening, physician visits, emergency room usage, and annual eye examination) of healthcare for this population. Potential correlates are socio-demographic factors, personal health conditions, insurance, health education (on diabetes, breast cancer etc.) exposure, and other health related factors.

Appendix D

Abstracts of Grants Awarded and Submitted

Grant awarded (R24, Agency for Healthcare Research and Quality; Grant Number R24HS017003)

UTPA Health Services Research Initiative

Year: 9/1/2007–8/31/2011

Principal Investigators: Cynthia J. Brown (2009-2011) and José A. Pagán (2007-2009)

The University of Texas-Pan American (UTPA) is the second largest Hispanic Serving Institution in the U.S. and it educates more Mexican American students than any other institution of higher education in the country. UTPA serves the educational needs of one of the poorest regions in the U.S.—the U.S.-Mexico border communities located in the Rio Grande Valley of South Texas. According to The University of Texas-Pan American Compact with the University of Texas System, the highest priority long-term initiative of UTPA for the next ten years is to become the doctoral research university of South Texas. In order to achieve this objective, UTPA is interested in developing new graduate degree programs and in increasing the research capacity and productivity of its faculty, especially in areas of regional strategic significance such as health services research. This AHRQ M-RISP application seeks to develop a Health Services Research (HSR) Initiative within the UTPA Institute for Population Health Policy (IPHP) to strengthen the research environment at UTPA and to enhance the competitiveness of faculty members in health services research. The research activities to be undertaken under the HSR Initiative primarily focus on health disparities and health care utilization/access for priority populations—more specifically, low-income minority populations in the U.S.-Mexico border and the uninsured. The HSR Initiative also takes advantage of an ongoing collaborative partnership between the IPHP and the Leonard Davis Institute (LDI) of Health Economics at the University of Pennsylvania. The LDI will provide technical expertise, mentoring and support to the proposed HSR Initiative. The Specific Aims of this M-RISP application are: (1) to develop a Health Services Research Initiative at UTPA, (2) to enhance the capacity of individual faculty members to undertake health services research, with a focus on research in low-income minority populations and the uninsured, and (3) to develop and foster research dedicated to reducing health and health care access disparities among Latino populations, particularly in the U.S.-Mexico border region. The HSR Initiative will support four individual investigator research projects which deal with community uninsurance and health care access, the use of health care services in the U.S.-Mexico border region, severe weather and health care use by low-income and uninsured vulnerable populations, and the cost-effectiveness and net-benefits of school-based health promotion programs. The proposed HSR Initiative will also actively promote the development of research projects by junior faculty and graduate students which focus on the U.S. Latino population and are consistent with the goals and objectives of both AHRQ and the UTPA-IPHP HSR Initiative.

Grant submitted (R21, National Cancer Institute, National Institutes of Health)

Health Literacy/Numeracy, Perceptions, and Breast Cancer Screening Uptake/Adherence

Year: 4/1/2012–3/31/2014

Principal Investigators: Cynthia J. Brown and José A. Pagán (NIH Multiple PI Grant Submission)

About one of every eight women in the US will develop breast cancer in their lifetime and there is evidence that early detection through mammography screening can lead to reduced mortality from breast cancer. Although studies have shown that health literacy and numeracy are associated with the ability of individuals to understand medical information and with cancer screening knowledge, the evidence linking these two important constructs to breast cancer screening uptake and adherence is weak, and the causal pathways by which health literacy and numeracy may impact breast cancer uptake and adherence are not well understood. Our long-term goal is to reduce the incidence of breast cancer—and its associated disparities and costs—by understanding the role of health literacy and numeracy in breast cancer screening uptake and adherence, and by developing appropriate evidence-based interventions. The objective of this proposal is to assess the role of health literacy and numeracy on breast cancer screening uptake and adherence using a novel modeling approach—a recursive, simultaneous-equation system linking health literacy and numeracy, personal perceptions, and screening uptake/adherence estimated using a conditional mixed process. The central hypothesis of the proposed research is that health literacy and numeracy may be related to breast cancer screening uptake and adherence through perceived rather than actual susceptibility, barriers, benefits, and knowledge about breast cancer. The specific aims of this project are to develop and estimate a structural model which links health literacy and numeracy, perceived breast cancer susceptibility, benefits, barriers, knowledge, and mammography uptake and adherence, assess structural differences in the model across different demographic and socioeconomic groups, and evaluate the predicted effect of improving health literacy and numeracy on perceptions and mammography uptake and adherence. The study will be conducted using a population-based sample of 2,000 women of screening age (40+ years of age) recruited from a national panel of about 50,000 participants selected using probability telephone and address-based recruitment methods. The findings from this research have the potential to identify policy levers that can be used to appropriately design breast cancer screening interventions and reduce health disparities across different demographic and socioeconomic groups.